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DEVELOPMENT DISSERTATION BRIEF

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EARLY CHILDHOOD DISABILITY: EVIDENCE FOR ENHANCED SCREENING AND SUPPORT

EBA

Early childhood disability: Evidence for enhanced screening and support

Anna-Theresia Ekman

Development Dissertation Brief, 2026:01
to
The Expert Group for Aid Studies (EBA)

Anna-Theresia Ekman defended her thesis on early childhood disabilities in June 2025. Anna-Theresia holds a bachelor's in nutrition from Stockholm University and a medical degree from Karolinska Institutet. In parallel with her PhD studies, she has been actively involved in teaching at university level and have placed strong emphasis on the so called third task – scientific communication aimed towards the public. She is currently doing her residency in paediatrics and continuing teaching and researching at the department for Global Public Health at Karolinska Institutet.

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Sammanfattning

Den här rapporten sammanfattar min avhandling ”Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support” (2025). Den lyfter fram ny forskning om situationen för små barn med funktionsnedsättning i Afrika söder om Sahara. Min forskning visar att funktionssvårigheter är vanliga bland barn och kopplade till sämre hälsa och utveckling. Studierna använder enkätdata från UNICEF, insamlad i Benin, Eswatini, Komorerna, Nigeria och Sierra Leone. I flera länder har 6–9 procent av små barn funktionssvårigheter. Studierna som ingår i avhandlingen bekräftar att barn med funktionssvårigheter har högre risk för sjukdom och försenad utveckling, vilket i sin tur tydliggör vikten av tidig upptäckt och snabba åtgärder. Studierna bekräftade också kopplingen mellan kronisk svält och fattigdom med risken för barn att inte nå åldersrelaterade utvecklingsindikatorer. Resultatet understryker behovet av fortsatt fattigdomsminskning, förbättrad tillgång till näringsriktig mat och stärkta primärpreventiva insatser.

En kvalitativ studie från Uganda visade starkt stöd för förebyggande insatser, liknande det svenska BVC-programmet, som kan identifiera barn i riskzonen tidigt och ge familjer kontinuerlig vägledning och stöd. Sådana förebyggande rutinuppföljningar för barn framstod som en lovande modell. Insatserna är ett sätt att integrera utvecklingsuppföljning med nutritionsstöd, kopplat till olika fattigdomsreducerande åtgärder. Att inkludera åldersadekvata utvecklingskontroller i rutinbesöken banar väg för en strategi som kan nå alla barn med hälsofrämjande åtgärder, och parallellt säkerställa att barn med utvecklingsförseningar eller funktionsnedsättningar får riktat och specialiserat stöd. Slutligen måste globala riktlinjer adapteras och utformas i nära samarbete med lokala hälsoarbetare och myndigheter för att vara genomförbara och accepterade.

Abstract

This developmental brief summarizes the main findings of my thesis ”Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support” (2025). My research shows that functional difficulties are both common and strongly linked to poorer health and development. Across multiple countries, 6–9 percent of young children—and even more in some contexts—face functional difficulties, and a large proportion of all children are at risk of not reaching developmental milestones. These risks are closely tied to stunting and poverty, underscoring the need for continued poverty reduction, improved access to nutritious food, and strengthened primary prevention. Studies within the thesis reaffirm that children with functional difficulties experience substantially higher odds of illness and developmental delay, highlighting the importance of early detection and timely intervention.

Stakeholder perspectives from Kampala, Uganda, further revealed strong support for preventive approaches that can identify at-risk children early and offer families continuous guidance. Well-care visits emerged as a promising model: a way to integrate developmental monitoring with nutrition support and poverty-reduction linkages, while also providing universal health promotion for all children. Embedding disability-inclusive developmental checks within these routine visits creates a practical, community-accepted strategy that can reach every child while ensuring that those with developmental delays or disabilities receive targeted and specialised support.

Introduction

Many children live with some type of disability. The disabilities vary in type and severity, and to what extent children will be affected by them depend largely on factors in the surrounding society. If supported, negative consequences of disability can be mitigated, strengthening children's development, positively impact families' economies, and empower communities.

My thesis focuses on young children with developmental disabilities using data from the Sub-Saharan African region (Figure 1 and 2). It explores how many children that may need targeted support, and how these children are doing in terms of health and development.

It then zooms in on the region of Kampala in Uganda, a country with long-lasting development and research collaborations with Sweden, to investigate how the concept of well-care clinics ("barnavårdscentraler" in Swedish) is perceived and can be established in a Ugandan context.

The results can guide efforts to strengthen children living in resource-limited environments by focusing on a topic in which Sweden has extensive experience and knowledge. At the same time, new knowledge can contribute to development of preventive health services in Sweden.

Background and rationale

Children learn and develop through play, social interactions, and early learning activities. It is therefore no surprise that child development is affected by the living conditions in which a child is born and raised.

In countries that struggle with poverty, poor health, food insecurity, and conflict, there is often a high number of children with disabilities, likely due to the large number of risk factors combined with weaker policies and services that strengthen child development.

This also means that child development can be optimized through a range of different measures, which thereby improve health and well-being later in life, positively impact on the whole family, and help communities to thrive long-term. Looking at it from a different angel, a community with thriving children is typically a community that is doing well.

Disability in early childhood

Disability occurs when an individual has an underlying health condition or impairment which interacts with personal or environmental factors, resulting in an activity limitation or participatory restriction (1).

The most common types of disabilities among young children are neurodevelopmental. Neurodevelopmental disabilities is a group of persisting conditions which starts before the age of two, and cause impairments of academic, personal, or social function (2). Disabilities can range from mild, where some support, adjustment or medical intervention may be enough, to severe, where the child may require life-long support.

Common neurodevelopmental disorders include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), communication disorders, cognitive impairments, cerebral palsy, learning disability, and some sensory impairments such as hearing and vision impairments. It is often unknown what the etiological cause is for an individual, and it seldom matters to know this to provide the right type of support.

Risk factors for child disability overlaps with risk factors for child mortality, and includes for example perinatal events including birth asphyxia, malnutrition (including stunting), infectious diseases such as cerebral malaria and encephalitis and injuries. Continued work to diminish the major causes of child mortality will therefore also decrease risks to acquire a neurodevelopmental disability.

Children with disabilities are excluded from development efforts

Typically, children with neurodevelopmental disabilities are often excluded from different development initiatives, despite the fact that children with neurodevelopmental disabilities typically have worse development and health outcomes (3). One important reason for the exclusion of children with development disabilities is that they in almost all settings, face stigma. In many contexts, the disability may be seen as a punishment for something the parents, typically the mother, did. Sometimes, the community shuns the family in fear of the disability or of bad luck rubbing off on others.

It may also be difficult for children with disabilities to access health and education services. For example, parents may need to carry a child with a movement disability long distances to access medical services. This may be doable with young children, but as the child grows it becomes harder. It may also be difficult for a child with disability to attend regular education. Attention deficits, sensory sensitivity and learning disabilities may hinder them to work well in a large group with little special education support.

Increased care need hinders the parents from generating income and puts the family in a position where they must choose between holding a job and caring for their disabled child. This is an example of the disability-poverty cycle, where unaccommodated disabilities keep families in poverty.

Children’s development can be supported

In early childhood, neurodevelopment is a fast process. Already before conception, a women’s health and social situation will affect the preceding pregnancy. When the foetus is developing in utero, development will be affected by the woman’s health and nutrition status. After the child is born, continuous and massive neurodevelopment will take place during the first two years of life. This period is known as “the first 1000 days” and provides an important window to support children’s development.

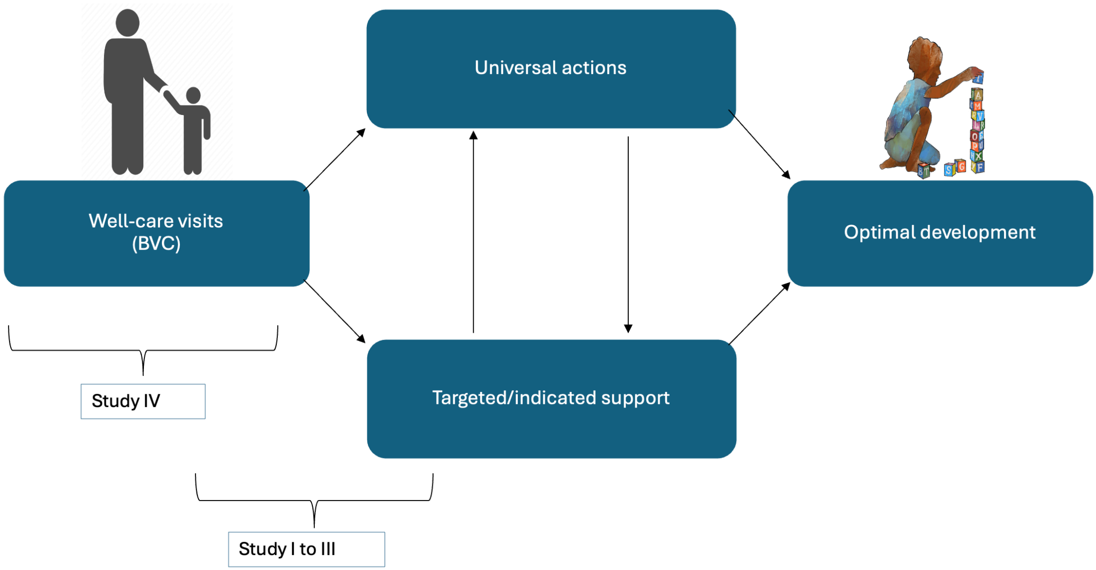
The Nurturing Care Framework provides a policy structure for interventions known to support early child development, emphasising health, nutrition, security and safety, responsive caregiving, and early learning. For young children below the age of three, the health sector has been recognized as well-placed to implement nurturing care activities (4).

Developmental monitoring and screening can identify children who may benefit from early intervention, assistive devices, tailored education, and family counselling — contributing to improved future school readiness, earning potential, and long-term functioning. Screening tools vary in complexity and resource requirements, and several tools have been designed specifically for use in low-resource settings.

Integrating developmental monitoring into routine preventive health care—such as well-care visits—offers an opportunity to deliver universal health promotion alongside targeted and indicated support. A recent scoping reviewed have highlighted the many forms and variations of “well-care visits” and similar models that exists (5).

As health systems transition toward more integrated models, routine well-care visits can provide structured touchpoints for continuous monitoring, nutrition and poverty-reduction measures, and timely referrals. Guided by the Nurturing Care Framework, countries can employ a twin-track approach that delivers universal actions for all children while ensuring that those with developmental delays or disabilities also receive targeted and specialised interventions (Figure 1). Such combined strategies help mitigate the effects of adversity and strengthen children's developmental trajectories from the earliest stages of life.

Figure 1. Example of a twin-track approach supporting optimal development and overview of included studies



Source: Ekman AT. Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support. PhD thesis. Karolinska Institutet; 2025.

How common are disabilities among young children?

To develop appropriate programs for health and well-being for children with disabilities, it is crucial to understand how many children that need support. This is no easy task, as prevalence estimates vary depending on type of methodology used. On a global level, disability among children below five has been estimated to 4.3 percent (29 million) using UNICEF data and 7.5 percent (50 million) when using data from the Global Burden of Disease study (6). There are also a number of studies that estimate the prevalence of either specific neurodevelopmental disorders or developmental delay in general (7–9).

There are several ways to measure disability. Counting cases of specific underlying neurodevelopmental impairments will give some insight, but many children have more than one type of disorder (meaning we cannot simply add numbers), and correct diagnoses require multiprofessional teams of health experts that consider a plethora of differential diagnosis. In a low-income setting, this can typically be done only when substantial resources are given to a specific project. Utilizing a biopsychosocial approach bypasses this issue, by instead focusing on the occurring disability. It also aligns with international policy documents such as the UN Convention on the rights of persons with disabilities (CRPD) and refrains from systems putting too much focus on diagnoses.

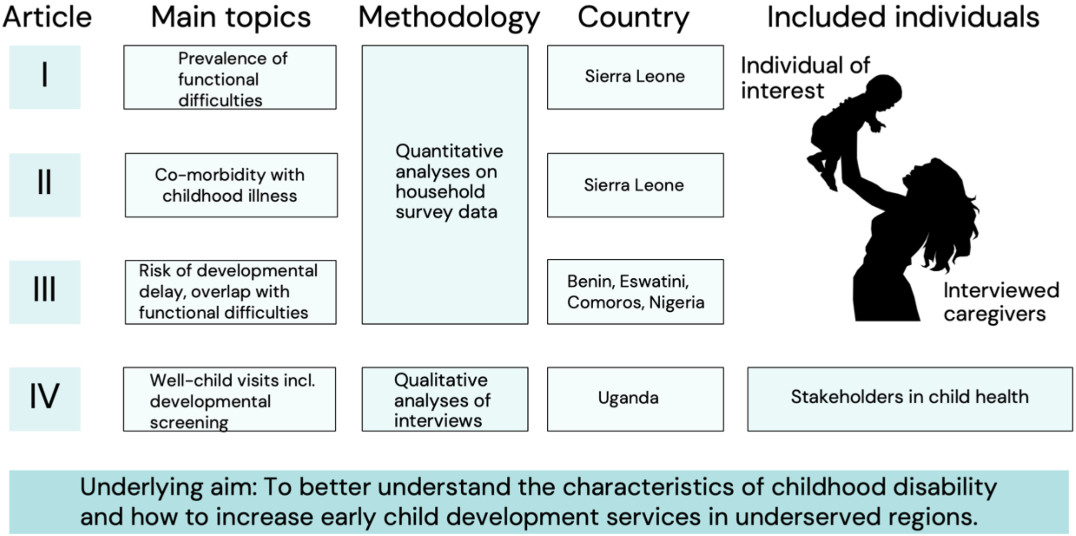
Research aims

My thesis explored the distribution of childhood disability and how preventive childcare activities delivered through well-care visits are viewed by stakeholders in child health (Figure 2). To achieve this overall aim, the thesis had four research aims:

1. To estimate the prevalence and characteristics of children living with signs of neurodevelopmental disorders in Sierra Leone using Multiple Indicator Cluster Surveys.
2. To investigate how symptoms of infectious diseases correlated to functional difficulties among young children in Sierra Leone.
3. To estimate the prevalence of being developmentally off-track or at risk of disabilities among children living in six different countries in Sub-Saharan Africa and understand how the two measures compare.

4. To explore how stakeholders in child health living in Kampala, Uganda, envision the concept of expanded preventive child health activities.

Figure 2. Overview of thesis



Article	Main topics	Methodology	Country	Included individuals
I	Prevalence of functional difficulties	Quantitative analyses on household survey data	Sierra Leone	Individual of interest Interviewed caregivers
II	Co-morbidity with childhood illness		Sierra Leone	
III	Risk of developmental delay, overlap with functional difficulties		Benin, Eswatini, Comoros, Nigeria	
IV	Well-child visits incl. developmental screening	Qualitative analyses of interviews	Uganda	Stakeholders in child health

Underlying aim: To better understand the characteristics of childhood disability and how to increase early child development services in underserved regions.

Source: Ekman AT. Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support. PhD thesis. Karolinska Institutet; 2025.

Methodology

The studies include, in total, data collection from six countries in Sub-Saharan Africa (Figure 2). Africa is a large and diverse continent, meaning that while these countries have some things in common, even more sets them apart. The Republic of Uganda is an East African country on Lake Victoria. The Union of the Comoros is an island nation in south-east Africa, and the Kingdom of Eswatini is in southern Africa. Three countries – the Republic of Benin, the Federal Republic of Nigeria and the Republic of Sierra Leone – are located within the West African Region. While Nigeria has Africa's largest population, Comoros has a population of less than one million. Most countries have many tribes and cultural groups, but Eswatini, for example, has a culturally homogeneous population dominated by the Swazi community. The uniqueness of each country is important to bear in mind when interpreting the results.

Methods are described briefly in Figure 2. In study one to three, large survey data sets collected through UNICEF and country statistical offices were used. In study four, qualitative data collected through interviews and focus groups with stakeholders was used. For detailed descriptions, including ethical reasoning, please refer to the full thesis and the four included studies.

Measuring disability among children through UNICEF data

Data on disability was collected through the child functioning module, introduced by the United Nations Children's Fund (UNICEF) as a means to provide robust population estimates of childhood disability (10–12). It builds on the biopsychosocial module and is designed to be integrated in regular nationally representative household surveys: Multiple Indicator Cluster Surveys (MICS). The MICS system was established in 1995 and have collected data on health, education and well-being in over 120 countries (13). New data collection rounds are continuously being rolled out, with the current round being the seventh. The introduction of the child functioning module therefore provides opportunity to collect data on childhood disability on a scale not previously possible. MICS data is available for research through the UNICEF MICS head quarter.

The child functioning module askes caregivers to rate how well the child is performing within different functional domains, comparing the child to other children of the same age on a Likert-like scale[1]. For young children (two to four years), the module collects data on seeing, hearing, mobility, dexterity, communication, learning, behaviour, and playing. If the child is rated above a pre-decided threshold, it is categorized to have a functional difficulty – a proxy

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[1] A Likert scale is a survey tool (a rating scale), that measures how strongly people agree or disagree with a statement, typically using a 5- or 7-point scale.

for children at risk of disability. For a more precise diagnosis, another approach with multiprofessional teams is required, which is difficult to implement at scale for data collection purposes in low-resource settings.

Results

This section summarizes my thesis with emphasis on results relevant for Swedish international development aid and aid policy. Results from several studies are presented side by side when relevant for policy discussion.

Survey data from five countries – Benin, Comoros, Nigeria, Eswatini, and Sierra Leone, were utilized to investigate what groups of children that had functional difficulty. Overall, functional difficulties were common: The prevalence of children at risk of disability was 6.6 percent (95% CI 5.8–7.6%) in Sierra Leone, 6,8 percent (CI 5.6–8.1%) in Comoros, 7.6 percent (CI 6.9–8.3%) in Nigeria, and 8.9 percent (CI 8.1–9.8%) in Benin. The prevalence was substantially higher in Eswatini, at 14.1 percent (CI 12.2–16.3%).

The data collected from the UNICEF MICS child functioning module showed consistency over a diverse set of countries, with functional difficulties being between 6–9 percent in all countries except Eswatini. It was also more common among boys and young children, in all countries except Comoros (see Table 1).

Table 1. Weighted prevalences of functional difficulties among young children

	Nigeria	Benin	Comoros	Eswatini	Sierra Leone
Total number of children	16 631 (100%)	7918 (100%)	2721 (100%)	1367 (100%)	7090 (100%)
Children with functional difficulties	1259 (7.6%)	704 (8.9%)	184 (6.8%)	193 (14.1%)	471 (7%)
Children with severe functional difficulties	746 (4.5%)	412 (5.2%)	78 (2.9%)	139 (10%)	126 (2%)
Two or more functional difficulties	231 (1.4%)	101 (1.3%)	48 (1.7%)	30 (2.2%)	124 (2%)
Not reaching developmental targets	8664 (52%)	4699 (59%)	1169 (64%)	711 (52%)	-

Source: Ekman AT. Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support. PhD thesis. Karolinska Institutet; 2025.

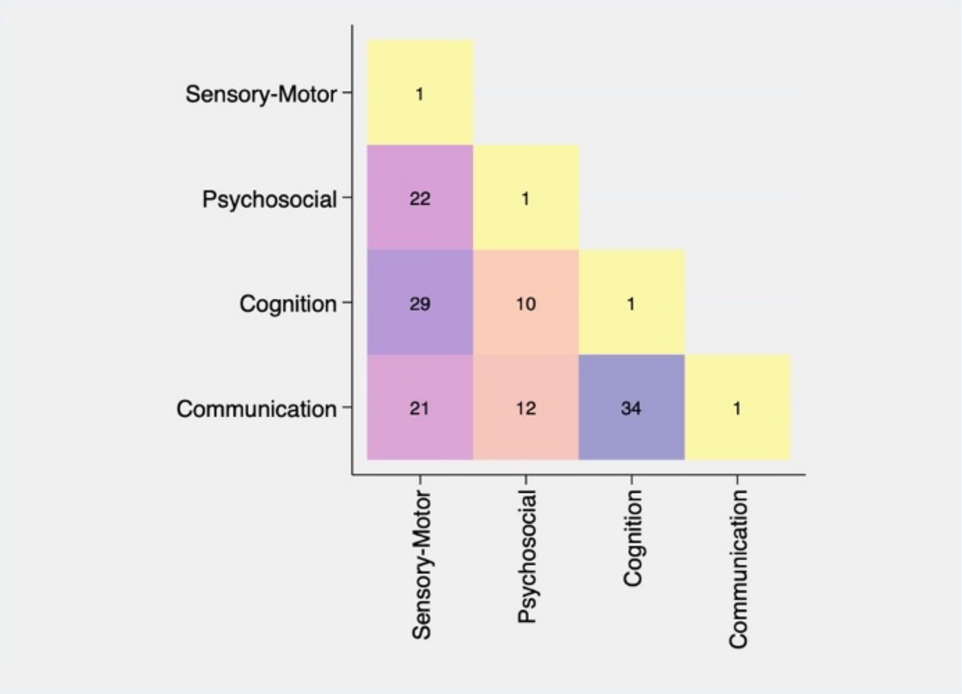
In Sierra Leone, a sub-study highlighted that there was a high risk of comorbidity between different types of functional difficulties. If a child had functional difficulties in one domain, the odds of having functional difficulties in an additional domain drastically increased (Figure 3).

Poor health and development outcomes in children with disability

Across countries, children with functional difficulties had higher odds of adverse health and development outcomes. In one study, young at risk-children in Sierra Leone had 30 percent higher odds (AOR 1.3, 95% CI 1.1 - 1.8) of fever compared to other children, which increased to 60 percent for children with severe functional difficulties (AOR=1.6, 95% CI 1.0 - 2.7). There was also a higher risk of diarrhoea (AOR=1.8, 95% CI=1.1 to 3.3) if the child had more severe functional difficulty. The study also investigated the risk of having acute respiratory infection, a proxy for pneumonia, but no difference in risk could be detected.

Approximately two thirds of all children with functional difficulties did not reach developmental milestones (Figure 4). Except in Comoros, children identified as being at risk of disability were more prone to falling below developmental milestones across four investigated countries. Further, the general prevalence of children at risk of not reaching developmental milestones was above 50 percent in all four investigated countries (52% (CI 49–55%) in Eswatini, 52% (CI 51–54%) in Nigeria, 59% (CI 58–61%) in Benin and 64% (CI 61–66%) in Comoros) (Table 1). There were clear associations with poverty and stunting.

Figure 3. Weighted, crude odds ratios estimating comorbidity between functional domains among children two to four years in Sierra Leone



	Sensory-Motor	Psychosocial	Cognition	Communication
Sensory-Motor	1			
Psychosocial	22	1		
Cognition	29	10	1	
Communication	21	12	34	1

Sensory-motor difficulties = functional difficulties of seeing, hearing, walking and fine motor skills.

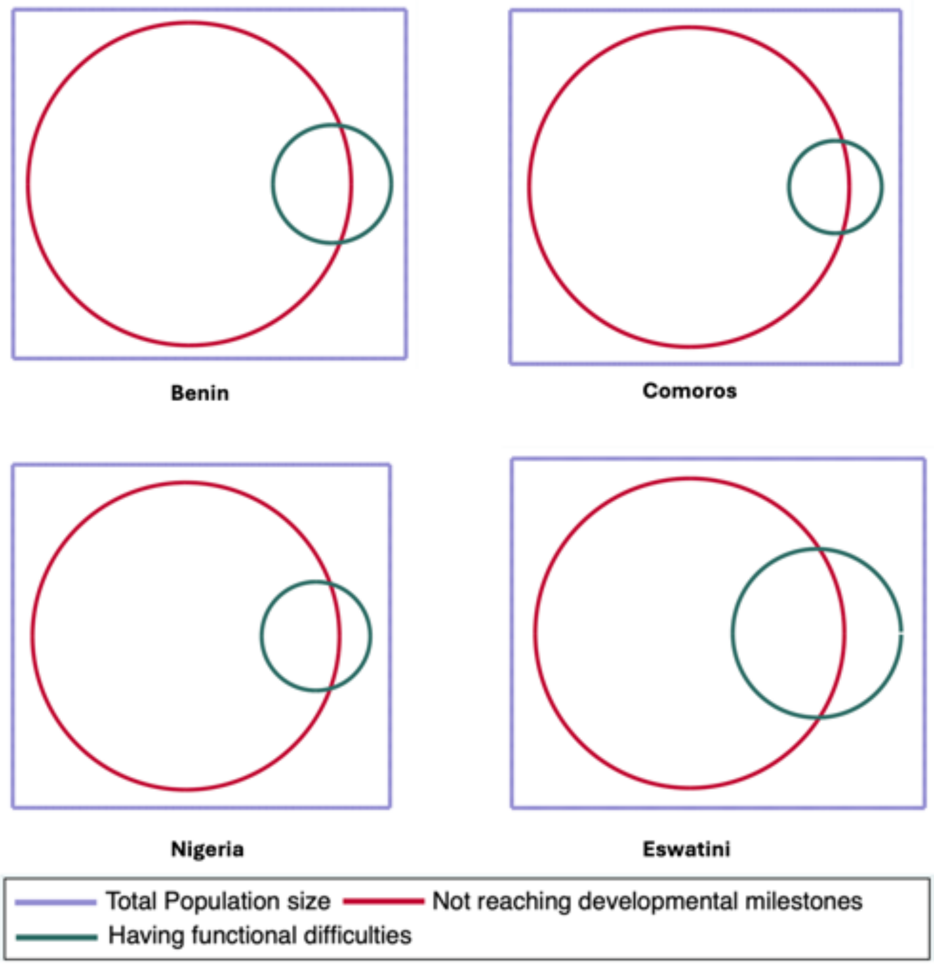
Psychosocial difficulties = controlling behaviour and playing.

Cognition = learning difficulties.

Communication = difficulties understanding or being understood.

Source: Ekman AT et al. Prevalence of children under five with disabilities in Sierra Leone: insights from a population-based Multiple Indicator Cluster Survey, Disability and Health Journal. 2023 Oct;16(4):101481.

Figure 4. Overlap of percentage of children with functional difficulties and children not reaching their developmental targets



Source: Ekman AT. Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support. PhD thesis. Karolinska Institutet; 2025.

Strong support for preventive child-care services

Study four shifted focus from understanding the distribution and risks for children at risk of disability, to instead look into the concept of preventive care for young children. Group interviews as well as individual interviews were conducted with over 80 participants in different societal capacities in Kampala, Uganda (Table 2).

Through transcript analyses, we concluded that there was a strong preference toward prevention rather than cure. Also, interviewees in general had noticed large improvements in both the health of children and visible disability rates during the preceding decades. This was attributed to the scale-up of preventive health activities such as vaccination (including polio) and distribution of impregnated mosquito nets.

Table 2. Interviewed stakeholder groups in preventive child health

Stakeholder group	Example
Parents and caregivers	Younger and older parents. Grandparents. Nannies and maids.
Actors outside the health sector	Community representatives, implementors, political and religious leaders.
Technical experts	In nutrition, immunization, child development, climate change.
Healthcare actors	From all levels of the healthcare system.
Media, health information, dissemination	Journalists, influencers.

Source: Ekman AT. Early childhood disability: Evaluating the burden and generating evidence for enhanced screening and support. PhD thesis. Karolinska Institutet; 2025.

Participants noticed that children with disabilities were harmed in the prevailing organization of healthcare and had large difficulties to receive care from trained health professionals.

> "If there were resources for the children with disabilities... This is because we always give them referrals, yet they don't have transport. … Because that also make us sad… You never know if there was a lot of help *[to be received],* then the child would have been helped…"
>
> Grandmother and village health extension team worker

To address these short-comings, increased knowledge on best practices of care for children with neurodevelopmental disorders was also asked for by all stakeholders. Health professionals and local authorities pointed out the need to identify and support children with disabilities effectively.

Some individuals, most notably children with disabilities or single and/or young mothers, were seen as having higher risks of poor health and thereby needing additional focus. The increased burden of care hindered caregivers from earning income. The system with maids, often untrained girls or young women, that provides a large bulk of informal child-care in Uganda, were perceived as particularly harmful to children with disabilities. The need for improved self-sufficiency and financial support or adjusted working conditions for carers in general, but specifically for careers of children with disabilities, was continuously highlighted.

Common grounds for preventive child health care

To shift focus from merely curative to preventive care as well, participants saw a need to find children with higher risk of poor health early, for example through universal programs with regular checkups. The use of such programs was considered being eligible for a small fee, but there was no consensus among study participants on how often these types of checks should occur. Community health workers were seen as a resource to anchor such programs within the community.

To ensure the success of well-care programs, stakeholders emphasized that services should be integrated, sustainable and reliable. I will now reflect on these three aspects, as they were mentioned in the study material. A full thematic analysis is presented in the thesis.

Integrated services

Integration emerged as a foundational principle across all discussions. Participants argued for vertical integration, within the health system, as well as horizontal integration, between health services, social support structures, and educational initiatives. Many suggested that child health would benefit from a local coordinating function capable of, when needed, structuring interventions around the child, particularly for children with disabilities, whose needs often span multiple domains. Integrated surveillance of children's health was seen as equally important: community health workers need access to timely, individual-level information to follow up with families and identify risks early.

Caregivers emphasized that well-child visits need to occur within communities rather than requiring long or costly travel to distant facilities. Health facilities should welcome children regardless of who accompanies them, reflecting daily realities where mothers' work responsibilities often force them to delegate childcare tasks. Participation in preventive care was seen as dependent on convenience and inclusivity.

Sustainability

Sustainability, as described by participants, involves designing child health systems that endure and continue to function effectively without overburdening the individuals who uphold them. Preventive strategies must be both scalable and rooted in existing community strengths.

For interventions to be sustainable, participants stressed the importance of investing in community knowledge and skills. Caregivers, community leaders, teachers, and health workers all requested structured opportunities to learn, adapt, and update their practices. A sustained flow of trusted information would help families respond appropriately to health issues as they arise, rather than depending on occasional campaigns or non-governmental initiatives. Sustainable development also requires recognizing that improvements take time. Participants cautioned against short-term projects and urged a unified approach capable of being implemented consistently across all regions of Uganda.

Sustainability was also mentioned within the economic sphere. Economic stability and accessible childcare options were seen as crucial for ensuring that caregivers can meet their responsibilities without undue hardship. Investments in early childhood education and locally available childcare services would lighten the burden on parents while contributing to children's development and well-being.

Finally, sustainable child health systems depend on listening to families—the end-users of services. Participants advocated involving beneficiaries at every stage of intervention development, whether through local councils or community structures connected to health services. Their involvement would ensure that initiatives remain grounded in real needs and retain long-term relevance.

Reliability

Reliability was repeatedly described as a cornerstone of effective child health. While participants appreciated Uganda's well-written national policies, they widely agreed that implementation remains inconsistent. At the community level, this inconsistency was perceived as a broken promise—evidence that commitments made at national level do not always translate into tangible improvements in people's daily lives.

For many, reliability meant that policies should move from paper to practice through well-planned and well-supervised projects. Detailed, long-term planning of health services was considered essential, as was closer monitoring of the population's health status to guide decision-making. Such monitoring, when done responsibly, was typically seen as legitimate and necessary. Participants urged stronger adherence to national child health policies, arguing that this would strengthen the social contract between government and citizens.

Reliability also depends on trust in the individuals' delivering services. Although caregivers trusted the professional competence of healthcare workers, they were less certain that these workers consistently acted in families' best interests. Doubts were reinforced by experiences of hidden or informal costs, sometimes amounting to outright corruption. These costs discouraged families from seeking care, particularly when combined with travel expenses and income lost through time away from work. Participants therefore stressed the need for transparent services delivered by competent, trustworthy people.

Community health workers were seen as reliable partners—individuals who understand local conditions and are well-positioned to identify children in need of services. However, community health workers already carry workloads beyond what they are compensated for, and work-related expenses such as water or mobile internet strain their personal finances. Participants cautioned that adding responsibilities without corresponding support would jeopardize the reliability of this vital workforce. Strengthening the work force requires not only training but also fair compensation and systematic backing within the overall health system.

Discussion and remarks

My thesis contributed to the expanding knowledge on children with disabilities living in countries in Sub-Saharan Africa. My thesis confirms previous studies that have repeatedly shown linkages between disability and lowered outcomes in health and quality of life (15-19). Although the disability itself will explain some outcomes, many adverse effects can be mitigated by implementing preventive health and habilitation services. Children with disabilities will for the foreseeable future remain a vulnerable group, with children with neurodevelopmental disabilities being at increased risk of stigma.

When support for health systems strengthening and global health research, as well as development aid, is scaling down, active effort is needed to keep focus on this group of children. Failure to do so will result in worsened health outcomes and lowered quality of life for children and their careers and contribute to keeping families in poverty. Strengthening the connection between child disability and general child health agendas can potentially improve outcomes for children with disabilities as well as for other children. Historical trends, such as the decline in cerebral palsy prevalence alongside reduced child mortality in Europe (20), and evidence from rural Kenya where neurological impairments decreased due to enhanced public health measures (21), illustrate this potential. Achieving progress toward the 2030 Agenda goals demands multisectoral collaboration across health, education, and agriculture sectors, with the health system well placed to coordinate these efforts for young children.

Well-care visits: A method for improved child health

While national policies supporting preventive care are well developed in many countries, including Uganda, a significant implementation gap persists at the community level, where frontline workers often face challenges translating strategies into practice. Bridging this gap requires stronger alignment between policy and local action, supported by coordinated leadership and capacity building.

The strong links between early childhood development, child disability, and stunting suggest that preventive services can be effectively combined with nutrition and poverty reduction programs. Such integrated approaches, supported by the Nurturing Care Framework align closely with the concept of well-care visits commonly used in high-income countries.

However, implementing these programs in resource-limited settings poses challenges, including overburdened and underpaid health workers. While well-care visits are useful for prevention and early detection, they must be complemented by targeted interventions for children with developmental delays or disabilities. Since the Nurturing Care Framework currently does not prioritize these children, expanding services requires careful planning to ensure inclusivity and avoid further marginalization.

Utilizing open-source data from the United Nations

MICS provides a unique opportunity to over time collect critical public health data, parallelled only by the Demographic Health Surveys developed by USAID (14). The technical support provided through UNICEF ensures that there is methodologic consistency between surveys and countries. Most countries have agreed to share their collected data with UNICEF and make it available for legitimate research purposes. By utilizing these data sets to better understand health needs to inform stringent policy, we make use of an important common good.

The disability measure used in the MICS, "functional difficulty", has several limitations. It is only a proxy measure, which does not translate to a child having a disability. In fact, there are many reasons why a child may have functional difficulty at a given time, including development delay. Functional difficulty is also not linked to specific diagnoses, meaning that we cannot know the exact aetiology as to why a child have difficulties. However, the proxy measure (functional difficulty) does provide information about the proportion of the population that may need support. It is also a measure that is simple enough to collect in surveys, enabling the same method to be used in different countries and at different times which allows for comparison.

Sweden´s unique position to support efforts in child development

Over the past century, Sweden has moved from charitable, segregated care for children with disabilities toward a rights-based, inclusive, domestic system. Early efforts in the late 19th and early 20th centuries relied on specialized institutions for blind, deaf, and intellectually disabled children, with limited focus on education or family life. The mid-20th century included harmful practices, such as the Vipeholm experiments and official recommendations for institutionalising young children. A major shift came with the Act on Support and Service to Certain Disabled Persons (LSS) in 1993, which guaranteed rights to personal assistance, respite care, habilitation, and family support—foundations that continue to guide disability policy today. While inequalities remain, Sweden's trajectory reflects a long-term transformation from segregation toward a rights-based, inclusive framework in which children with disabilities are entitled to support enabling full participation in society.

Parallel to this, Sweden also has a strong universal system for preventive child care. Its well-care clinics ("barnavårdscentraler"), established in the 1940s when child mortality was still high, have alongside aspects such as long-lasting peace, economic growth, and a comprehensive social security system, played a central role in achieving today's exceptionally low mortality rates. These nurse-led clinics provide structured, preventive child health services: Regular check-ups, vaccinations, and parental support. Their mission lies closed to newly released guidelines on well-care visits from UNICEF and the World Health Organization. Sweden's national experience demonstrates how accessible, integrated preventive care can significantly improve child survival, offering valuable insights for countries such as Uganda seeking to strengthen child health and development.

Conclusion

In conclusion, the findings are consistent in four of the five countries studied, and the data corroborate health and development risks identified in other research. This reinforces confidence in the reliability of MICS data to inform health policy. The analyses indicate that children with functional difficulties face significantly elevated risks to their health and development, underscoring the need for policies that prioritise early detection and timely intervention.

Several Sub-Saharan African countries also show strikingly high proportions of children at risk of not reaching key developmental indicators. Combined with strong links to stunting and poverty, the findings highlight an urgent policy imperative: reducing poverty, improving access to adequate and nutritious food, and strengthening primary prevention must remain central to child health strategies.

Stakeholders emphasized the need for durable, community-driven solutions to improve child health, highlighting the importance of a co-design approach that actively involves beneficiaries in designing interventions. To avoid creating parallel systems, efforts should focus on adapting, integrating, and scaling existing programs, such as the recommended well-care visit schedules. These visits offer valuable opportunities for ongoing, reliable health education, a key demand from communities in Uganda.

The findings further suggest that integrating developmental monitoring with nutrition and poverty-reduction initiatives into routine well-care visits could be an effective approach to reach all children while prioritising those at highest risk. Successful implementation requires a collaborative, co-design approach, supported by strong local leadership and active engagement of frontline workers and community stakeholders. Such an approach ensures that interventions are context-appropriate, scalable, and capable of improving development outcomes for children.

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This brief summarizes research findings that shows that functional difficulties affect 6–9% of young children across several countries in sub-Saharan Africa and are strongly linked to poor health, developmental delay, stunting, and poverty. Evidence from a study in Kampala, Uganda, supports early detection through disability-inclusive well-care visits integrating prevention, nutrition, and family support.

Olika funktionssvårigheter påverkar 6–9 procent av små barn i flera länder i Afrika söder om Sahara och är starkt kopplade till ohälsa, tillväxthämning och fattigdom. Förebyggande insatser, som liknar det svenska BVC-programmet, har enligt evidens från en studie som genomförts i Kampala, Uganda, potential att identifiera barn i riskzonen och ge familjer kontinuerlig vägledning och stöd.

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