Identification of children with disabilities

Review of existing tools, surveys and recommendations for GIZ

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Abbreviations

AHC Angkor Hospital for Children

AU African Union

BILIC Bandung Independent Living Centre

BMZ Bundeministerium für wirtschaftliche Zusammenarbeit und Entwicklung

(Federal Ministry for Economic Cooperation and Development)

CBR Community Based Rehabilitation

CF Child Functioning

CIPS Cambodian Inter-Sensal Population Survey

CRPD Committee on the Rights of Persons with Disabilities

DAC Disability Action Council

DHS Demographic Health Survey

DEval Deutsches Evaluierungsinstitut der Entwicklungszusammenarbeit gGmbH

(German Institute for Development Evaluation)

DMAT Developmental Milestone Assessment Tool

ES-F Extended Set on Functioning

GERKATIN Movement for the Welfare of Indonesia's Persons with Hearing

Impairment

GIZ Deutsche Gesellschaft für Internationale Zusammenarbeit

GOI Government of Indonesia

GOT Government of Tanzania

HC Health Centre

HEF Health Equity Fund

HI Handicap International

ICF International Classification of Functioning

ILO International Labour Organization

INGO International Non-Governmental Organisation

IMCH Improved Maternal and Child Health Programme

MDS Model Disability Survey

MICS Multi Indicator Cluster Survey

MoMT Ministry of Manpower ad Transmigration

MoP Ministry of Planning

MoSA Ministry of Social Affairs

Muskoka GIZ Improving and Maternal Newborn Project in Cambodia

NDSP National Disability Strategic Plan

NGO Non-Governmental Organisation

OHCHR Office of the High Commissioner of Human Rights

PERTUNI Indonesian Blind Union

SAPDA Centre for Advocacy for Women with Disabilities and Children

SEHATI Association of persons with disabilities in Sukoharjo

SIGAB Legal Aid for Inclusion and Disability Advocacy

SUPAS Survey Penduduk Antar Survey (National Intercensal Population Survey)

SUSENAS Survei Sosial Ekonomi Nasional (National Socio-Economic Survey)

UN United Nations

UNCRC United Nations Convention on the Rights of the Child

UNCRPD United Nations Convention on the Rights of Persons with Disabilities

UNESCAP United Nations Economic and Social Commission for Asia and the Pacific

UNESCO United Nations Educational, Scientific and Cultural Organisation

UNICEF United Nations Children's Fund

SPP Social Protection Programme

SUPAS Survey Penduduk Antar Sensus (National Intercensal Population Survey)

SUSENAS Survey Sosial Economic Nasional (National Socio-Economic Survey)

TGPSH Tanzanian German Programme to Support Health

WG Washington Group

WHO World Health Organization

WHODAS World Health Organization Disability Assessment Schedule

Glossary

Accessibility Accessibility describes the degree to which an environment, service, or

product allows access by as many people as possible, including persons with

disabilities.1

Barriers Factors in a person's environment that, through their absence or presence,

limit functioning and create disability – for example, inaccessible physical environments, a lack of appropriate assistive devices, and negative attitudes

towards disability.2

Community Based Rehabilitation (CBR)

A strategy within general community development for rehabilitation, equalisation of opportunities, poverty reduction, and social inclusion of persons with disabilities. CBR is implemented through the combined efforts of persons with disabilities themselves, their families, organisations, and communities, and the relevant governmental and nongovernmental health,

education, vocational, social, and other services.3

DisabilityPersons 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.4

Disabled People's Organisation (DPO)

Organisations or assemblies established to promote the human rights of disabled people, where most the members as well as the governing body are

persons with disabilities.5

Impairment In the ICF loss or abnormality in body structure or physiological function

(including mental functions), where abnormality means significant variation

from established statistical norms. ⁶

International Classification of Functioning, Disability and Health (ICF) The classification that provides a unified and standard language and framework for the description of health and health-related states. ICF is part of the 'family', of international classifications developed by the World Health

d Health (ICF) Organization.

Mainstream services Services available to any member of a population, regardless of whether they

have a disability – for example, public transport, education and training, labour and employment services, housing, health and income support. 8

Physiotherapy Provides services to individuals to develop, maintain, and maximise

movement potential and functional ability throughout the lifespan. Also

known as physical therapy.9

Reasonable accommodation

Necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities enjoy or exercise, on an equal basis with

others, all human rights and fundamental freedoms. 10

¹ WHO, 2011, p. 301

² WHO, 2011, p. 302

³ WHO, 2011, p. 302

⁴ Convention on the Rights of Persons with Disabilities, Article 1.

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#1

⁵ WHO, 2011, p. 303

⁶ WHO, 2011, p. 305

⁷ WHO, 2011, p. 306

⁸ WHO, 2011, p. 306

⁹ WHO, 2011, p. 307

¹⁰ WHO, 2011, p. 308

Rehabilitation A set of measures that assists individuals who experience or are likely to

experience disability to achieve and maintain optimal functioning in

interaction with their environment. 11

Twin Track Approach

Work on disability and to promote gender equality often use a twin track approach. This is a combination of:

Mainstreaming:

In the disability sector this includes working to identify and overcome the barriers in society that persons with disabilities face, e.g. physical accessibility, communication, attitude, legislation, and including persons with disabilities into all aspects of development.

Targeted activities that respond to particular needs or areas of inequality:

For disability, this includes supporting and empowering persons with disabilities, their families and representing organisations through increasing their access to support services, health care, education, livelihood and social activities as well as through political empowerment.¹²

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Foreword

I would like to thank the following people for their support during the preparation of this paper:

- Mr Lars Wissenbach, Advisor Sector Initiative Inclusion of Persons with Disabilities at GIZ office in Bonn
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- Mr Piet de Mey, Regional Advisor on Inclusive Development Asia at GIZ office in Phnom Penh
- Ms Cut Sri Rozanna, Program Director Social Protection Program at GIZ office in Jakarta
- Ms Elizabeth Diana Perwita Sari, National Advisor for Inclusion of Persons with Disability at GIZ office in Jakarta
- Mr Tolhas Damanik, Consultant Expert for Inclusion of Persons with Disability
- Mr Mahlil Ruby, National Advisor for Social Health Insurance GIZ office in Jakarta
- Mr Philipp Bornschlegl, Development Advisor for Tanzanian German Programme to Support Health (TGPSH) & Improved Maternal and Child Health Programme (IMCH) at GIZ office in Dar Es Salam

Background

Children with disabilities are a particular vulnerable group. Early detection of child development delays and/or impairments is crucial as the first three years of a child's life are a critical period. If not identified as early as possible, these conditions can threaten the development of children and may have lifelong impacts. Not reaching certain milestones by a certain age is a developmental warning sign or red flag. Children who do not reach those milestones may need extra support and services to reach their full potential. Once delays are detected, those children need to be referred for professional assessment. When confirmed, early intervention needs to be ensured in medical and physical rehabilitation (as well as other means of support), enabling them in the long run to participate fully in the society to their full abilities.

At the same time, such identification processes form a crucial precondition for the access of persons with disabilities to adequate health care, rehabilitation and social protection. The access of children with disabilities to health services is often even more limited, leading to health and other inequalities unconnected to their disabilities. Most children with developmental delays are not identified in time for them to benefit from early intervention services. Too often, signs of a potential developmental disability are not recognized within their environment. The identification and targeting of persons with disabilities in general and children with disabilities in particular is a worldwide challenge. The lack of identification makes them an invisible group for potential early care support, either with regard to public service providers or (GIZ) development programs. Therefore, monitoring each child's development can help to systematically

assess potential needs with regard to general and specific services as well as preconditions for accessing amongst other the health, social protection and education system.

While the quality and implementation of approaches to measure disability prevalence and disaggregate census and survey data on disability increased over the past years, the identification of children with disabilities up to the age of five still remains a major challenge. At the same time, GIZ health, child health and social protection programs from different regions as well as other development stakeholders require valid approaches and tools to address this issue and indicate the need for a simple tool to identify young children with disabilities.

The objective of this short-term project is to set up a GIZ task force, including colleagues from both GIZ programs in Asia and Africa, in order to share information, experience and expertise with regard to the identification of children with disabilities through the development and implementation of approaches to identify children with disabilities.

Based on experiences gathered in Cambodia and other countries, the task force aims at pooling expertise of GIZ projects and relevant partners to develop guidelines to identify culturally appropriate child developmental milestones and establish respective screening tools for children aged 0-5 years.

Frameworks and guidelines for the German development cooperation

United Nations Convention on the Rights of the Child (UNCRC)

The United Nations Convention on the Rights of the Child's article 23 makes it mandatory for all ratifying parties of the UNCRC to ensure that a

"... disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community." (UN, 1989)

This is only achievable if quality data on children with disabilities has been collected and made available to all parties concerned in order to both inform the development and implementation of individual assistive arrangements and to ensure the accessibility of public spaces and services.

United Nations Convention on the Rights of Persons (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities urges governments in article 31 to collect data on persons with disabilities. The data collection shall be implemented according to international human rights- and technical standards:

'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention ...' (UN, 2006)

As of October 2017, the convention has been ratified by 174 countries and is therefore legally binding for them. Germany ratified the convention on 24th February 2009 (OHCHR, 2017). Article 32 of the UNCRPD urges state parties to include the concerns of persons with disabilities in their international cooperation and to ensure that cooperation is inclusive.

Agenda 2030 & Sustainable Development Goals (SDGs)

The UN's Agenda 2030 for Sustainable Development acknowledges the gap of available disability data to measure progress towards the SDGs as well as the need for capacity building to strengthen data collection systems. (UN, 2015, p. 13) Agenda 2013 therefore urges all UN member states

'... to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts' (UN, 2015, p. 27)

All SDGs are important for inclusive and peaceful worldwide development and relevant for persons with disabilities. However the following SDGs are especially relevant for the disability sector:

Table 1: Disability sector relevant SDGs



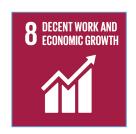
Ensure healthy lives and promote well-being for all at all ages.

SDG 3 aims at reducing the mortality rate of newborns and children and access to quality health care for all, including persons with disabilities.



Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.

SDG 4 focuses on eliminating gender disparities and equal access to all levels of education for all, including persons with disabilities. It also calls for an upgrading of education facilities to be child, disability and gender sensitive and at the same time provide safe, inclusive and effective learning environments.



Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all.

SDG 8 aims at achieving full and productive employment and decent work for all women and men including women and men with disabilities on a basis of equal pay.



Reduce inequality within and among countries.

SDG 10 focuses on strengthening the social, economic and political inclusion of all, including persons with disabilities.



Make cities and human settlements inclusive, safe, resilient and sustainable.

SDG 11 calls on developing accessible, safe, affordable and sustainable public transportation that caters also for the needs of persons with disabilities. SDG 11 also demands the provision of and universal access to safe public spaces.



Strengthen the means of implementation and revitalize the global partnership for sustainable development.

SDG 17 stresses that the collection of quality data is crucial for monitoring progress towards the SDGs. Children with disabilities benefit from improved data collection mechanisms in relation to SDG 3 and SDG 4.

African Union Continental Plan of Action for the African Decade of Persons with Disabilities 2010 – 2019

The African Union (AU) reaffirms the need for quality data collection disaggregated by gender on persons with disabilities. (African Union Commission - Department of Social Affairs, 2010, p. 15) AU member state therefore shall *improve gaps in data regarding disability in rural areas and facilitate information sharing to all stakeholders*. (African Union Commission - Department of Social Affairs, 2010, p. 29)

Incheon Strategy to "Make the Right Real" Disabilities in Asia and the Pacific

The Incheon Strategy's goal 8 states that data on persons with disabilities in the Asia and the Pacific region is still inadequate. Various definitions of the terminologies *disability* and *persons with disabilities* that have been used contribute to the situation. Goal 8 calls on states to develop data collection systems that are based on the ICF by age, sex, race and socioeconomic status. (UNESCAP, 2012, pp. 31-32)

BMZ Action Plan for the Inclusion of Persons with Disabilities

In 2013, the BMZ developed its *Action Plan for the Inclusion of Persons with Disabilities* on the basis of the UNCRPD. Pillar two of the action plan urges the German development cooperation to '... foster the inclusion of persons with disabilities in our partner countries.'. Three sub-objectives have been formulated to achieve this: (BMZ, 2013, p. 10)

- > Mainstream inclusion of persons with disabilities in planning and review mechanisms.
- > Implement twin-track approach for disability inclusive development by promoting disability specific interventions and rolling out new disability inclusive developments programmes.
- > Develop knowledge, understanding and skills of development staff.

With views on data, this shall lead to '... scientifically collated data on the inclusion of persons with disabilities at international level ...' and to '... needs-driven and informed engagement, and allow us to disseminate examples of positive lessons learned in inclusive development cooperation.' (BMZ, 2013, p. 15)

The German Institute for Development Evaluation (DEval) evaluated the BMZ Action Plan for the Inclusion of Persons with Disabilities in 2016/17. The evaluation came to the conclusion that 'the overarching goal of this action plan ... the systematic mainstreaming of the inclusion of persons with disabilities in German development policy' was achieved in low to moderate proportions. (Schwedersky, Ahrens, & Steckhan, 2017, p. vii)

The action plan will be followed by a supra-sectoral strategy in 2018. Based on the recommendations of the evaluation, the future strategy will include a strong focus on the support of the disaggregation of data by disability through German development cooperation.

Methodology

Literature review

The literature review included the assessment of relevant publication and websites of UN agencies, scientific articles, publication of GIZ projects, national laws and regulations and other publications. A full list of documents is available in the bibliography at the end of this paper.

Questionnaire

A questionnaire has been designed to gather information about the following GIZ programmes in Cambodia, Indonesia, and Tanzania:

Table 2: GIZ programmes consulted

Country	Name of programme
Cambodia	Muskoka – Improving Maternal and Newborn Care Project
Indonesia	SPP – Social Protection Programme
Tanzania	TGPSH – Tanzanian German Programme to support health
	IMCH – Improvement of maternal and child health

The questionnaire covers questions about involvement of persons with disabilities including children in the programme; access to data; need for data; how quality data has the potential to support the programme; data collection; and challenges during data collection. The full questionnaire is accessible in annex 8.

Skype conference calls

To achieve a better understanding of GIZ programmes in Cambodia, Indonesia and Tanzania Skype calls have been arranged with programme representatives in the countries. The following Skype conference calls have been held:

Table 3: List of Skype conference calls

Location	Date	Participants
Bonn &	29 th August 2017	Mr Lars Wissenbach, Advisor – Sector Initiative Inclusion of
Phnom		Persons with Disabilities (Bonn)
Penh		Mr Klaus Baesel, Junior Advisor – Improving Maternal and
		Newborn Care Project (Phnom Penh)
		Mr Piet de Mey, Regional Advisor on Inclusive Development Asia
		(Phnom Penh)
	26 th September 2017	Mr Piet de Mey, Regional Advisor on Inclusive Development Asia
		(Phnom Penh)
	17 th October 2017	Mr Piet de Mey, Regional Advisor on Inclusive Development Asia
		(Phnom Penh)
	19 th October 2017	Mr Piet de Mey, Regional Advisor on Inclusive Development Asia

		(Phnom Penh)
	25 th October 2017	Mr Piet de Mey, Regional Advisor on Inclusive Development Asia (Phnom Penh)
Jakarta	13 th September 2017	Ms Cut Sri Rozanna, Program Director – Social Protection Program Ms Elizabeth Diana Perwita Sari, National Advisor for Inclusion of Persons with Disability Mr Tolhas Damanik, Consultant Expert for Inclusion of Persons with Disability Mr Mahlil Ruby, National Advisor for Social Health Insurance
Dar Es	14 th September 2017	Mr Philipp Bornschlegl, Development Advisor for Tanzanian German
Salaam		Programme to Support Health (TGPSH) & Improved Maternal and Child Health Programme (IMCH)

International overview

This section provides a summarized overview on the understanding of disability also known as *models of disability*. This part will discuss the terms *impairment*, *disability* and *barriers*. They are crucial terminologies for the understanding of current disability models.

The next part presents different kinds of *data sources*. This part discusses the individual characteristics and strengths of each data source.

The third part discusses the prominent data collection tools and discusses their usage.

Models of disability

Five models of disability are discussed here. Each model offers a different understanding of disability and persons with disabilities. Since the moral, charity and medical are outdated, only a brief description is given. More emphasise is paid to the social and biosocial model.

Moral model

The moral model describes of disability as a curse or a punishment given by an external force that might have resulted from wrongdoings of ancestors in the past or as a result of sinful behaviour of parents.

Charity model

In the charity model of disability, persons with disabilities are seen as week and in need of pity and charity. Mainstream society beliefs that persons with disabilities are not able to live independently and need to be looked after. Very much focus is given to what a person with a disability cannot do instead rather than what she or he is able to do and how they can she or he can be empowered.

Medical model

Over the last decade, the perspective of persons with disabilities has shifted from focusing on impairment and therefore the loss of function of the body and the need to "fix" the person – known as the medical model of disability – to recognising the rights of persons with disabilities and the importance of removing barriers in the environment / society in order to including them in all aspects of life. The out-dated medical model of disability viewed disability as a mere medical issue that can be cured or relieved through medical interventions. The medical model of disability is not compatible with current

human rights based approaches to disability as enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and other frameworks.

Social model

The 2006 UN Convention on the Rights of Persons with Disabilities declares in its preamble that

"... disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others, ..." (UN, 2006)

Having said this, the UNCRPD changes the **paradigm on how societies understand disability**:

Disability results from the interaction of a person with an impairment with society if society has developed barriers for the participation of persons with disabilities. Societies that remove barriers to participation create inclusive environments that enable all persons – including persons with disabilities – to have access to public services as well as facilities and participate in communal live. They are therefore included. "Fixing the environment" by removing *barriers* to participation leads to mediation of the impact of the functional limitation on the quality of life of the person and reduced *disability*.

The new framework does not contain any new rights, but applies existing human rights to the specific situation of persons with disabilities. The change that the UNCRPD has brought is that persons with disabilities are active subjects with rights that they can claim. This reaffirms the paradigm shift from viewing persons with disabilities as objects of charity and pity to subjects with rights. The social and rights-based model of disability declares that

- Disability is the result of interaction of an individual with society.
- Disability does not lie within the individual.
- Society creates barriers (e.g. attitudinal, environmental, policies, etc.) and therefore disables the participation of some individuals.
- Under the social model, society must change so that barriers for individuals are removed.

Biosocial model (ICF)

The biosocial model according to the ICF seeks to determine a person's disability status on three domains (WHO, 2002, p. 10):

Table 4: Three domains of the ICF

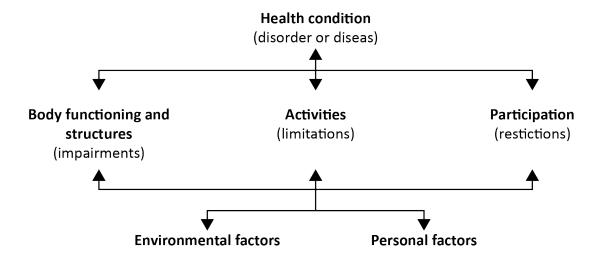
Domain	Description	Influenced by
Body functioning then structures	Functioning at the level of the body.	Impairments.
Activity	Functioning at the level of the individual. Activities are deliberate action to accomplish a task.	Activity limitations.
Participation	Functioning of a person as a member of society. Participation refers to activities that are integral to economic and social life.	Involvement of people in all areas of live and participation restrictions they experience.

The three domains are influenced by (WHO, 2002, p. 10):

- > **Personal factors**, such as gender and age, mental and emotional status.
- > **Environmental factors**, such as accommodation for impairment in the body functioning domain.
- > Health condition, such as disorders or diseases.

Therefore, disability in the ICF arises out of limitations and restrictions due to the interaction of *body structure and functioning* and *unaccommodating environment* influenced by personal factors and health condition.

Figure 1: Biosocial model of disability according to ICF 13



Examples of the applied ICF are in annex 1.

Kind of data sources

There are many different ways to raise statistical population data. A common form is the national census that asks a generic set of questions about all members of a population. Household surveys nowadays often include a module on disability. Each of the data sources outlined below has its own strengths and limitations when it comes to collecting data on persons with disabilities and especially young children with disabilities. (Cappa, Collecting Data on Child Disability, 2014) (Cappa, Petrowski, & Njelesani, Navigating the landscape of child disability measurement: A review of available data collection instruments, 2015)

National censuses

A population census represents a **complete enumeration** of the population including every household and no sampling. Population censuses are very costly endeavours due to the large number of persons to be covered. Characteristics covered in a population census are carefully chosen and limited to keep the costs of the endeavour under control. National population censuses are usually implemented every ten years.

Household surveys

Surveys are more specific and detailed than censuses. Surveys are often used to get more specific data and information on a **sample of the population** selected from other instruments like for instance censuses. Surveys are often specialised and focus on

-

¹³ See WHO (2002), p. 9

different topics such as agriculture, education, labour, health, socio-economic issues, or welfare. The specialisation of the survey depends on the field of work of the institution.

Administrative records

Early childhood centres, schools, universities, social security systems, rehabilitation programmes, civil registration bureaus and many other government institutions gather administrative data to manage and monitor programmes. The purpose of this datasets is to monitor the implementation of a programme towards the achievement of a national action plan or development policy. As this kind of data is collected for a specific purpose it can give a far more in-depth overview on a population accessing a certain government service.

Clinical assessments

Clinical assessments of children are detailed, lengthy and resource rich examinations of a child. The examinations include assessments of a child's health, observations on its behaviour in different situations of daily living, reports from parents, early childhood care and school teachers and others. The information gathering process is lengthy and includes consultations with an inter-disciplinary team of professionals that are not limited to health professionals only. Clinical assessments can give useful insights for studies about the causes of disability¹⁴, planning and monitoring prevention strategies and counselling approaches.

Qualitative studies

Qualitative studies are essential for understanding disability and give better understanding to the number and statistics gathered in censuses, surveys and administrative records. Qualitative studies are limited to a selected population or selected environment but have the potential to gather many different voices. They have the potential to give answers to subjective feelings and draw a picture of cultural attitudes, beliefs and traditions that either enhance or reduce disability. Qualitative studies are especially useful tools in environments where no data are available as questions and methods can be adapted to the local context.

¹⁴ See Social model: interaction with society as a cause of disability

Disability data collection tools

UN Washington Group on Disability Statistics (WG)

The Washington Group is one of currently nine active United Nations Statistics Commission City Groups. ¹⁵ The Washington Group consists of representatives of national statistical offices and works in close cooperation with UN agencies, bi-lateral donors, NGOs, DPOs and research institutions. The Washington Group was established in 2001 due to the need for international comparable data on persons with disabilities. The Washington Group developed several sets of questions for different age groups and purposes. The sets of questions can be integrated into larger surveys or censuses. (Washington Group on Disabilty Statistics, 2017)

Short Set of Questions

The Short Set of Questions was the first tool developed by the WG. The questions purpose is to identify whether people have challenges performing basic activities of daily life in six domains (seeing, hearing, walking, remembering, self-care, communicating). The WG Short Set of Questions is displayed in table 4 to give the reader an idea how the WG questions are formulated. The other WG question sets are formulated in a similar manner and available in the annexes. The six questions and possible answers are as followed:

Table 5: WG Short Set of Questions

No.	Questions	Answers				
1	Do you have difficulty seeing , even if	No - no	Yes - some	Yes - a lot of	Cannot do at	
	wearing glasses?	difficulty	difficulty	difficulty	all	
2	Do you have difficulty hearing, even if	No - no	Yes - some	Yes - a lot of	Cannot do at	
	using a hearing aid?	difficulty	difficulty	difficulty	all	
3	Do you have difficulty walking or	No - no	Yes - some	Yes - a lot of	Cannot do at	
	climbing steps?	difficulty	difficulty	difficulty	all	
4	Do you have difficulty remembering or	No - no	Yes - some	Yes - a lot of	Cannot do at	
	concentrating?	difficulty	difficulty	difficulty	all	
5	Do you have difficulty (with self-care	No - no	Yes - some	Yes - a lot of	Cannot do at	
	such as) washing all over or dressing?	difficulty	difficulty	difficulty	all	
6	Using your usual (customary) language,	No - no	Yes - some	Yes - a lot of	Cannot do at	
	do you have difficulty communicating,	difficulty	difficulty	difficulty	all	
	for example understanding or being					
	understood?					

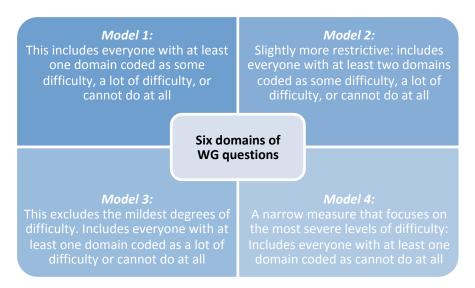
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¹⁵ See https://unstats.un.org/unsd/methods/citygroup/ for more information on active and completed United Nations Statistics Division City Groups.

The definition of disability and disability prevalence varies, depending on the defined threshold of functioning severity, number of difficulties in the given domains or both.

There are different approaches to define populations with and without disabilities. The prevalence depends on the cut-off to be used with the WG questions. Figure 2 shows four example models cut-offs to measure disability prevalence. (Statistics South Africa, 2017) Model 3 is the cut off recommended by the WG. (Washington Group on Disability Statistics, 2017)

Figure 2: WG questions cut-off models to determine disability prevalence



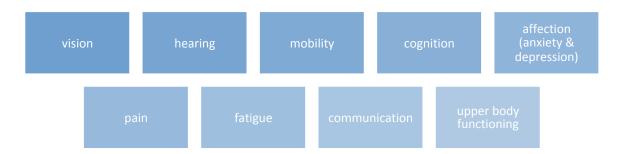
The selection of the disability measure model might differ from country to country or depending on the data collection purposes. For example, the Statistics Office of South Africa follows model 2, whereas disability is defined as having at least some difficulties in at least two domains. (Statistics South Africa, 2017)

The intention of the short set of questions is not to be used in isolation but to be integrated in larger population censuses or dedicated surveys. The short set of questions allows for the disaggregation over disability of the census or survey data. (Washington Group on Disability Statistics, 2017)

Extended Set of Questions on Functioning (ES-F)

While the short set of questions' intention is to be inserted into existing censuses or surveys, the goal of the extended set of questions on functioning is to collect data on disability where more information is required. The extended set of questions on functioning includes the following domains:

Figure 3: Domains of the WG extended set of questions



It also addresses issues such as assistive devices, age and environmental factors. (Washington Group on Disability Statistics, 2017).

The extended set of questions on functioning is accessible in annex 3.

Child Functioning Module (CF)

The WG realised that the two existing sets of questions have their limitations identifying children with disabilities. This is due to the reason that questions for adults are not always appropriate for children. For example, identifying communication problems in adults is easier that in children who are still developing these skills as part of their development.

Therefore, in cooperation with UNICEF, the WG developed two sets of questions for the identification of children age two to four years old and children age five to seventeen years old. The WG came to the conclusion that it is not feasible to identify disability among children below two years of age through censuses and surveys. The questions are designed to target the child's mother or primary caregiver. Both sets of questions expand on the functional domains of children, where disabilities are mainly related to intellectual functioning, affect and behaviour. Age appropriate challenges are identified by using questions that start with the phrase "Compared with children of the same age ...". The questions can be used as complementary questions sets for existing censuses or surveys. (Washington Group on Disability Statistics, 2017) For the moment, however, censuses and surveys which include the Washington Group Questions appear to focus on the short-set of questions for the population 5 years and or older due to limited resources, thus effectively excluding all children below that age. The question set for children age two to four years old is accessible in annex 4. The set for children age five to seventeen is accessible in annex 5.

A critique on the child functioning module relates to the way age related questions are formulated. The phrase "compared with children of the same age" leaves wide room for interpretation and not all children develop at the same pace. Some children are able to

perform certain activities earlier than others, some children later without having a developmental delay. The Denver II, Malawi and the Khmer Development Milestones Assessment Tools (DMAT)¹⁶ for instance document clearly the age window for specific skill developments in children which are country-specific.

Developmental Milestone Assessment Tool (DMAT)

The purpose of developmental milestone assessment tools is to monitor a child's development and screen children on possible developmental challenges or delays. ¹⁷ They are usually applied to children age zero to six years old. DMATs use performance indicators to monitor a child's development. Each indicator is given a certain time bracket measured in months. Should a child not meet a certain milestone in the specified age range, a warning sign or red flag is indicated and early intervention must be triggered. DMATs are able to describe different ranges of disability prevalence depending on where the cut-off for a developmental delay has been set. A cut-off set at 90% will generate a higher number of red flags than a cut-off of 100%. Annex 9 displays performance charts of the Denver II, Khmer and Malawi DMAT including different cut-offs. DMATs include indicators for fine motor-adaptive, gross motor, personal-social, and language skills. A well-known DMAT is the *Denver Development Screening Tool II* ¹⁸, which is accessible in annex 9.

DMATs are differing from WG questions and WG question implementations in DHS or MICS. Clinical personnel including medical doctors and physiotherapists in cooperation with the child's parents usually use DMATs. However, there have been efforts to develop DMATs based on the Social model¹⁹ that take the child's environment into consideration.

DMATs allow the collection of data of children below the age of two years old. To get valid information on the development of children it is necessary to adapt the developmental milestones to cultural norms of child developmental. A developmental goal for toddler of five months in Germany can be a developmental goal at a different age range if it grows up in Cambodia.

WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)

WHODAS 2.0 is an assessment tool that measures health and disability at population level or clinical practice. WHODAS 2.0 captures six functioning domains:

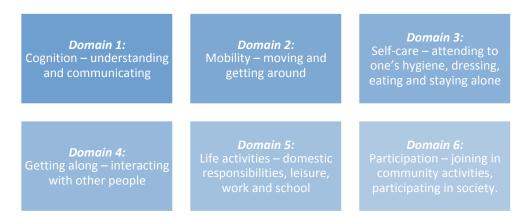
¹⁶ See further below in this chapter.

¹⁷ See: Data sources – Clinical assessments

¹⁸ See http://denverii.com/

¹⁹ See: Social model as well as AHC DMAT and Khmer DMAT

Figure 4: WHODAS 2.0 domains



WHODAS 2.0 is based on the WHO'S ICF²⁰ and therefore focuses on functioning and disability. WHODAS 2.0 is available in different version. The full version has 36 questions, while the shorter version features twelve questions. The different versions can be administered by an interviewer, by the persons themselves, or by a proxy. (WHO, 2010, pp. 4-5)

The WHODAS 2.0 does not feature yet a version for children or youth. (WHO, 2017)

Physical screening tools

Physical screening tools for newborn children are important tools to determine weather a newborn is in a healthy condition. They contribute to early detection and early intervention. Physical screening tools cover children up until six years old. They support health personnel with the identification of impairments and diagnosis of impairments and follow a medical model of disability²¹. The screening is usually followed up by medical rehabilitation interventions in case the screening identifies an impairment. There is a chance of under-identification of children with disabilities because children might have functional limitations undertaking life activities which do not manifest as impairments.



Biosocial model (ICF)
²¹ See: Medical model

Disability data sources

Demographic Health Survey (DHS)

Demographic Health Surveys (DHS) are household surveys that collect data on health related issues. The usual sample size is between 5,000 to 30,000 households. A DHS is conducted every five years to produce data that allows comparison. (DHS Program, 2017)

The current DHS of 2016 features a disability module that is based on the WG short set of questions and the child functioning module for children five to seventeen years old. The DHS disability module includes the following questions:

Table 6: DHS Disability Module Questions (2016)

DHS question number	Question	Answers	Based on WG ²²
26	Does (NAME) wear glasses or contact lenses to help them see?	1 = Yes 2 = No	CF1
27	I would like to know if (NAME) has difficulty seeing even when wearing glasses or contact lenses. Would you say that (NAME) has no difficulty seeing, some difficulty, a lot of difficulty, or cannot see at all?	 1 = no difficulty seeing 2 = some difficulty 3 = a lot of difficulty 4 = cannot see at all 8 = don't know 	CF2
28	I would like to know if (NAME) has difficulty seeing. Would you say that (NAME) has no difficulty seeing, some difficulty, a lot of difficulty, or cannot see at all?	1 = no difficulty seeing 2 = some difficulty 3 = a lot of difficulty 4 = cannot see at all 8 = don't know	CF3
29	Does (NAME) wear a hearing aid?	1 = Yes 2 = No	CF4
30	I would like to know if (NAME) has difficulty hearing even when using a hearing aid. Would you say that (NAME) has no difficulty hearing, some difficulty, a lot of difficulty, or cannot hear at all?	1 = no difficulty hearing 2 = some difficulty 3 = a lot of difficulty 4 = cannot hear at all 8 = don't know	CF5
31	I would like to know if (NAME) has difficulty hearing. Would you say that (NAME) has no difficulty hearing, some difficulty, a lot of difficulty, or cannot hear at all?	1 = no difficulty hearing 2 = some difficulty 3 = a lot of difficulty 4 = cannot hear at all 8 = don't know	CF6
32	I would like to know if (NAME) has difficulty communicating when using his/her usual language. Would you say that (NAME) has no difficulty understanding or being	 1 = no difficulty communicating 2 = some difficulty 3 = a lot of difficulty 4 = cannot communicate at all 	EF-S COM_1

²² CF = Child Functioning; ES-F = Extended Set of Questions on Functioning

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	understood, some difficulty, a lot of difficulty, or cannot communicate at all?	8 = don't know	
33	I would like to know if (NAME) has difficulty remembering or concentrating. Would you say that (NAME) has no difficulty remembering or concentrating, some difficulty, a lot of difficulty, or cannot remember or concentrate at all?	1 = no difficulty remembering / concentrating 2 = some difficulty 3 = a lot of difficulty 4 = cannot remember / concentrate at all 8 = don't know	EF-S COG_1
34	I would like to know if (NAME) has difficulty walking or climbing steps. Would you say that (NAME) has no difficulty walking or climbing steps, some difficulty, a lot of difficulty, or cannot walk or climb steps at all?	1 = no difficulty walking or climbing 2 = some difficulty 3 = a lot of difficulty 4 = cannot walk or climb at all 8 = don't know	EF-S MOB_1
35	I would like to know if (NAME) has difficulty washing all over or dressing. Would you say that (NAME) has no difficulty washing all over or dressing, some difficulty, a lot of difficulty, or cannot wash all over or dress at all?	1 = no difficulty washing or dressing 2 = some difficulty 3 = a lot of difficulty 4 = cannot wash or dress at all 8 = don't know	EF-S SC_1

Multi Indicator Cluster Survey (MICS)

MICS is a household survey tool developed by UNICEF. Until today, 295 MICS surveys in 108 countries have been implemented. MICS generate data on the well-being of children and women. The reports and data sets are available for downloading on the MICS website²³. (UNICEF, 2017)

The following MICS have been conducted in Indonesia and Tanzania (see table 6). No MICS has yet been implemented in Cambodia. (UNICEF, 2017) All MICS listed below have been finalised prior to the introduction of the WG modules on child functioning.

Table 7: MICS in Indonesia and Tanzania²⁴

Round	Country	Year	Reports	Datasets
MICS4	Indonesia (Papua Selected Districts)	2011	Final	Available
MICS4	Indonesia (West Papua Selected Districts)	2011	Final	Available
MICS2	Indonesia	2000	Final	Available
MICS1	Indonesia	1996	Final	Not available
MICS1	Tanzania, United Republic of	1996	Final	Not available

²³ MICS website: http://mics.unicef.org/

²⁴ No MICS has been implemented in Cambodia

MICS includes modules for children under 5 years old and children age 5 to 17. Both modules include sections on child functioning based on the respective WG question sets on child functioning. Therefore, the module for children under 5 years old however does not collect data on child functioning for children below 2 years of age.

The MICS questionnaire section on child functioning for children under 5 is accessible in annex 6. The questioner section for children age 5 to 17 years old in accessible in annex 7. The tables in annex 6 and 7 are complemented with references to the relevant WG question sets on child functioning.

Model Disability Survey (MDS)

The MDS is population survey that is based on the ICF. The MDS is based on the assumption that disability is an outcome of interactions between persons with health conditions and environmental and personal factors.

Up until today the MDS does not feature a module for children and is administered to adults age 18 and above. (WHO, 2017, pp. 6-7)

Country-specific overview

Cambodia

National legal guidelines

UNCRPD

The Royal Government of Cambodia (RGC) has ratified the UNCRPD on 20th December 2012 (OHCHR, 2017). No report to the CRPD has been submitted yet and no shadow report has been published.

National Disability Strategic Plan (NDSP) 2014-2018

The RGC developed in 2013 the National Disability Strategic Plan 2014-2018. The NDSP was published through the RGC's Disability Action Council (DAC). The DAC oversees the implementation of the NDSP and coordinates disability issues in Cambodia.

The 10 objectives of the NDSP are: (Disability Action Council, 2014)

Figure 5: Strategic Objectives of the NDSP



The NDSP uses data from the Cambodian Inter-Censal Population Survey of 2013 that identified 2.06% of the population having a disability (see below). Children with disabilities in the age between zero and fourteen years old have been identified with 10.63% of all persons with disabilities. (Disability Action Council, 2014, p. Acknowledgement) However, the RGC states in the NDSP that "Lack of disability data management systems and updates of disability data is inadequate and not specific." (Disability Action Council, 2014, p. 7).

Data

Inter-Ministerial Declaration on Classification of Types And Levels of Disabilities

With an inter-ministerial declaration in 2011, the RGC developed its own classification of disabilities which should be implemented by the Ministry of Health. The classification is not specific to children and is developed on a medical model point of view for physical

and sensorial impairments but focuses on functionality for disabling chronic diseases. It therefore does not include the principles of the ICF, UNCRPD or the WG questions sets.

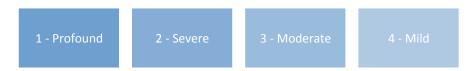
The declaration mentions four types of disabilities with *physical disability* having four sub-types:

Figure 6: Types of disability in Cambodian Declaration



Annexed to the declaration is a classification system for each of the four types of disability. The classification has the following levels:

Figure 7: Cambodian disability classification system

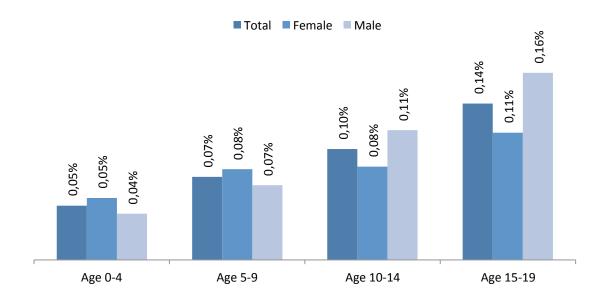


The majority of classifications come with medical indicators. For disabling diseases that affect the internal organs, the limitations measure limitations in personal activities and social life. For mental disability, the loss of ability to carry out work is measured. It is not specified how this is measured. (RGC, 2011, p. annexes)

Cambodian Inter-Censal Population Survey (CIPS)

The 2013 CIPS identified a very low number of persons with disabilities. 2,06% of the total population has been identified as having a disability (RGC, 2013, p. 12). The CIPS gathered data on disability over all ages in the population. This resulted in disability rates displayed in table 8. (RGC, 2013, p. 23)

Table 8: CIPS age & gender disaggregated disability prevalence



The WHO estimates that between 10%-15% of a population has some form of disability (WHO, 2011). The reason for this discrepancy is probably the way the only question on disability is formulated in CIPS: 'physical / mental disability, if any'. (RGC, 2013, p. 74) These kinds of questions on disability are less likely to motivate interviewees to indicate correct answers and generate low rates of disability. (Mont, SP Discussion Paper, 2007, p. 7)

Cambodian Demographic Health Survey 2014 (CDHS)

The 2014 CDHS uses the WG short set of questions. Data is analysed using the WG disability prevalence model 1 and 3^{25} .

Using disability prevalence model 1 it identifies that 9.5% of the population aged five and older have some form of disability. The survey shows that 5.1% of the population have difficulties seeing, 3.7% have difficulties hearing, 4.2% have difficulties walking or climbing stairs, and 4% have difficulties remembering or concentrating. Only 1.1% of the population has at least some difficulty with self-care and 1.5% with communicating. The prevalence of disability increases with age from 2% age 5-14 years old, to 3% age 15-34 years old, to 13% age 35-59 years old, and 44% age 60 and over. (National Institute of Statistics, Directorate General for Health, and ICF International, 2015, p. 42)

²⁵ See Figure 2: WG questions cut-off models to determine disability prevalence

Table 9: CDHS disability data - total and disaggregated by age, based on WG disability prevalence model 1

	No	Any	Seeing	Hearing	Walking	Concentrating	Self-	Communicating
	difficulty	domain					care	
Total	90.5	9.5	5.1	2.8	3.7	4.2	1.1	1.5
Age 5-14	98.2	1.8	0.3	0.5	0.3	0.7	0.6	0.5
Age 15-34	96.5	3.5	1.0	1.0	0.8	1.6	0.3	0.8
Age 35-59	86.8	13.2	6.6	2.7	4.4	5.2	0.7	1.2
Age 60+	55.7	44.2	30.5	17.0	22.3	21.5	6.9	7.9

Using disability prevalence model 3, the CDHS identifies 2.1% of the total population have a disability: 0.7% of the population have difficulties seeing, 0.6% have difficulties hearing, 0.9% have difficulties walking or climbing stairs, and 0.7% have difficulties remembering or concentrating. Only 0.5% of the population has at least some difficulty with self-care and 0.6% with communicating. The prevalence of disability increases with age from 0.5% age 5-14 years old, to 0.9% age 15-34 years old, to 2% age 35-59 years old, and 11.8% age 60 and over. (National Institute of Statistics, Directorate General for Health, and ICF International, 2015, p. 42)

Table 10: CDHS disability data - total and disaggregated by age, based on WG disability prevalence model 3

	Any domain	Seeing	Hearing	Walking	Concentrating	Self- care	Communicating
Total	2.1	0.7	0.6	0.9	0.7	0.5	0.6
Age 5- 14	0.5	0.1	0.1	0.1	0.2	0.2	0.5
Age 15-34	0.9	0.1	0.3	0.2	0.4	0.2	0.5
Age 35-59	2.0	0.4	0.4	0.9	0.5	0.3	0.6
Age 60+	11.8	5.3	3.2	5.5	3.6	3.0	2.2

The CDHS uses an old disability module that differs from the 2016 DHS disability module discussed in the chapter on Demographic Health Survey (DHS). The following set of questions and multiple-choice answers has been used. The table also indicates in the last column on which WG question the CDHS questions are based. (National Institute of Statistics, Directorate General for Health, and ICF International, 2015, p. 334)

Table 11: CDHS disability module

CDHS question number	Question	Answers	Based on WG ²⁶
21	Does (NAME) have difficulty seeing, even if wearing glasses	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot see at all 5 = don't know	CF2
22	Does (NAME) have difficulty hearing, even if using a hearing aid?	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot hear at all 5 = don't know	CF5
23	Does (NAME) have difficulty walking or climbing steps?	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot walk or climb at all 5 = don't know	EF-S MOB_1
24	Does (NAME) have difficulty remembering or concentrating?	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot remember / concentrate at all 5 = don't know	EF-S COG_1
25	Does (NAME) have difficulty with self-care such as washing all over or dressing?	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot do at all 5 = don't know	EF-S SC_1
26	Because of a physical, mental or emotional health condition, does (NAME) have difficulty communicating, (for example understanding others or others understanding him/her?	1 = no 2 = some difficulty 3 = a lot of difficulty 4 = cannot communicate at all 5 = don't know	EF-S COM_1

Conclusion

Observing the varying figures on number of persons with disabilities identified over the years through different censuses and surveys in Cambodia demonstrate the lack of consistency when it comes to measuring disability prevalence. This also applies to the issue of child disability data, which is not regularly collected. The CDHS of 2014 for instance does not collect data for children below the age of five years old.

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²⁶ CF = Child Functioning; ES-F = Extended Set of Questions on Functioning

The figure below displays the fluctuations in disability prevalence in several censuses and surveys in Cambodia.

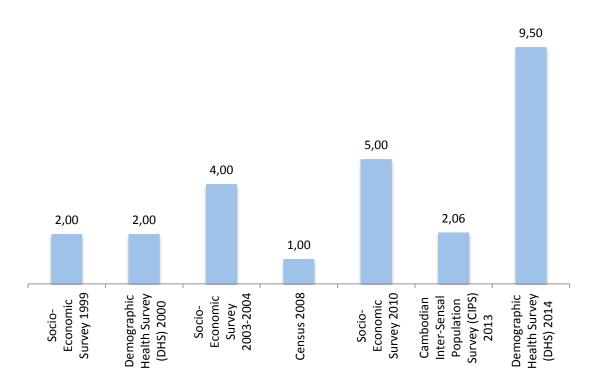


Figure 8: Percentage of persons with disabilities in Cambodian surveys 27

GIZ programme initiatives

IDPoor

IDPoor is a standardised poverty identification process that makes use of participatory measures to review identification results. The Ministry of Planning (MoP) started in 2005 developing the IDPoor system and GIZ began with its contribution and support in 2006.

IDPoor classifies poor households in two poverty levels: IDPoor 1 – very poor and IDPoor 2 – poor. The indicators are based on easily observable and verifiable assets and income. Other vulnerability indicators such as chronic disease, disability with WG questions, school enrolment and financial debt.

IDPoor data is used by government institutions, NGOs, UN and other institutions to give identified households access to: (GIZ, 2017)

- > Free health care services und the Health Equity Funds (HEF)
- > Cash transfers for pregnant women
- > School feeding and scholarship programmes

²⁷ Sources: (UNICEF, 2013); (RGC, 2013); (National Institute of Statistics, Directorate General for Health, and ICF International, 2015)

- > Disaster relief
- > Social land concessions
- > And many other services.

There are different questionnaires for urban and rural areas.

Currently the questionnaire for rural areas collects data on special household circumstances which cause reduction in living standard amongst which there is "Severely disabled head of household or spouse of head of household (unable to earn income, or spends money for treatment)". It provides the obligation for the village committee to debate whether they propose to change the poverty classification of the household based on the asset and income scoring system.

The questions and indicators used in the newly developed urban IDPoor questionnaire are adapted from the WG questions. Families with persons with disabilities score extra poverty score when it affects income.

Figure 9: Assessment of disability in urban IDPoor questionnaire

Seeing Hearing The questionnaire Walking allows household members to report on Remembering or concentrating th three most important Washing all over or dressing (self-care) functional difficulties: Communicating Other (specify) •no difficulty some difficulty ·a lot of difficulty •Cannot do at all

AHC DMAT and Khmer DMAT

Since the early 1990s, a number of different DMATs have been used in Cambodia to monitor child development but all of them were based on adapting the Denver II DMAT. The DMATs have ben used by local NGOs introduced by INGOs. Although the DMATs used have many things in common, differences prevail in definitions and implementation and feature the absence of standardised routines. The main shortcoming however was

that in the past the DMAT featured many milestones for which the age window was based on western performance references which do not reflect the Cambodian reality. (Angkor Hospital for Children & GIZ, 2017)

The DMAT, called the blue book DMAT, has been developed by INGOs assisting the rehabilitation sector. It does not standardize the milestone assessment and performance criteria (Pass-Fail) and used international performance charts, mainly based on Denver II. The Blue Book is a family stimulation guide which features child development stimulation games which can be applied at home to encourage children (with or without a delay) to acquire the specific skill measured in each milestone.

In 2007/8 the Angkor Hospital for Children (AHC) developed the AHC DMAT. The AHC DMAT is also based on the *Denver Development Screening Tool II*, and has been adapted to Cambodian culture and norms. In 2015, GIZ Muskoka facilitated an assessment of 1,440 children in three Cambodian rural and semi-urban districts after the assessment methodology and the pass and fail criteria were standardized in an AHC DMAT manual. The study made it possible to document the age range at which well-nourished rural and semi-urban Khmer speaking children are able to perform each of the 140 milestones of the AHC DMAT. The performance chart documents (Angkor Hospital for Children, 2015):

- > 38 milestones in the social / personal domain
- > 37 milestones in the fine motor domain
- > 33 milestones in the language domain
- > 32 milestones in the gross motor domain

See the table below for average age differences per domain and Annex 12 – Differences in performance (Cambodia, Malawi and Denver II) for individual milestone performance differences between cultures.

Table 12: Average difference ²⁸ in age-window of performance by domain (cDMAT 1, Malawi & Denver II)

Domain	Average month differences Khmer - Malawi	Average month differences Khmer - Denver II
Social	-2.67	2.34
Fine Motor	0.30	3.98
Language	-1.23	4.92
Gross motor	-1.13	1.23
Overall average	-1.18 months	3.11 months

The study also compared the inter-observer reliability. In late 2016 and early 2017 GIZ in Cambodia held workshops to further improve the reliability of those milestones with poor inter-observer reliability by scrutinizing the assessment methodology and

²⁸ Average of differences in PASS P25%, P75% and P90% for common milestones

performance criteria. The order of the milestones, also called the hierarchy, was adapted to reflect the performance curve in Khmer children. Four milestones were abandoned because they are of similar age-window performance (Angkor Hospital for Children & GIZ, 2017). The latest Khmer DMAT consist of 136 milestones:

- > 36 milestones in the social / personal domain
- > 34 milestones in the fine motor domain
- > 35 milestones in the language domain
- > 31 milestones in the gross motor domain

Based on the performance charts of the Khmer DMAT when 100% of the children in that age-cohort pass the milestone and on selecting very reliable milestones, a community-based DMAT (CB-DMAT) has been developed to be used at community or health centre level. The CB-DMAT screens children aged nine to sixty months old on developmental delays. The screening is done with only four questions (1 social, 1 fine motor, 1 social and 1 gross motor) for each of the six age brackets: (i) 9 to 17 months, (ii) 18 to 23 months, (iii) 24 to 35 months, (vi) 35 to 47 months, (v) 48 to 59 months, and (vi) 60 months and older. The CB-DMAT is accessible in annex 10. When a child cannot perform these milestones in their age category, they have a developmental delay and should be referred to a hospital for full DMAT assessment and medical check-up.

A physiotherapist in a hospital can conduct the Khmer DMAT on children expected with development delays. A medical doctor should examine the children with documented delays in order to rule out underlying diseases and come up, in dialogue with the caretakers, with an intervention plan. The physiotherapist can teach the parents on how to stimulate their child and refer to. CBR programmes for home interventions, based on the family training manual for child development stimulation. Parents and caregivers can do the activities with their children at home. (Montaufray, 2017)

Physical Screening of children with disabilities

The GIZ Muskoka programme developed physical screening protocols for health personnel in cooperation with Handicap International's Mother and Child Programme in Cambodia:

- > The *Physical Screening for Newborns (1 28 days): National Protocol* (HI & GIZ, 2017), and
- > the Physical Screening for Young Children (1 month 5 years): National Protocol (HI & GIZ, 2017).

Screening and early detection after birth and during early childhood is a very important step to prevent impairments and disability in the future. The above-mentioned

documents are developed for nurses and midwives in health centres or hospitals and other health professionals who are trained to use the screening protocols. It is the goal of the screening protocols that early detection leads to early intervention, which will reduce the impact of impairments after birth. Once an impairment or condition is identified, the child and the parents must be referred to a physician at a secondary health facility.

As discussed above, physical screening can help to identify children with disabilities early onwards, what is crucial to provide early support depending on the diagnosis. However, in terms of data collection, there are limitations as only children with disabilities will be pointed out, not necessarily all children with functional limitations. Thus, collected data can be important indications of early childhood disability prevalence rates, but does not provide a full picture of all children with functional limitations.

Conclusion

GIZ in Cambodia has contributed to the development of screening and assessment tools for children with disabilities and developmental delays up to the age of six years. Both physical screening tools and the Khmer DMAT can assist in providing necessary data to trigger early intervention. The Community Based Khmer DMAT has the potential to reach a wide range of people and support children's development. The cultural sensitive Khmer DMAT has the potential to identify children with impairments below the age of two years old and has the potential to fill up the gap that the WG questions leave open.

Indonesia

National legal guidelines

UNCRPD

The Government of Indonesia (GOI) ratified the UNCRPD on 30th November 2011 (OHCHR, 2017). Law number 19 of 2011 on the Ratification of the Convention on the Rights of Persons with Disabilities introduced the UNCRPD into the national legal system (GOI, 2011).

Law 8/2016 on Persons with Disability

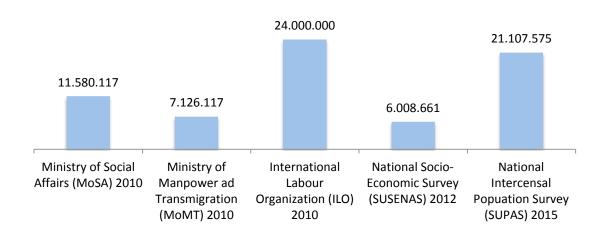
Just recently, the GOI published a new law on persons with disabilities. The new law is based on the principles of the UNCRPD and follows the same definition for disability. The law states that persons with disabilities have the right to be counted and registered as persons with disabilities with all their characteristics and must receive a 'disability card'. (GOI, 2016)

Data

Reports to the CRPD

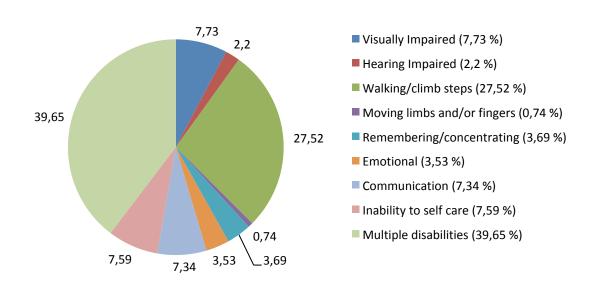
The GOI's first report to the CRPD states that Indonesia still faces challenges collecting quality data of persons with disabilities, due to different data collection methods. Currently several government institutions are collecting sectoral data. Different definitions of disability as well as different methods lead to varying results. The graphic below illustrates the huge differences in the total number of persons with disabilities identified. (GOI, 2016, pp. 40-41)

Figure 10: Number of persons with disabilities in surveys in Indonesia 29



Based on data from the 2015 SUPAS, the GOI's report, estimates that 1.904.298 children – 905.336 (2,46%) girls and 998.962 (2,58%) boys – aged 2-17 years old or 2,52% of the total population have a disability. (GOI, 2016, p. 38)

Figure 11: Estimated percentage of children with disabilities age 2-17 in Indonesia



The Indonesian Shadow Report on the implementation of the UNCRPD published by the Indonesian Disability Convention Team³⁰ confirms the data dilemma for Indonesia. The shadow report adds that government institutions are reluctant to allocate sufficient funds for data collection on persons with disabilities; that DPOs are not involved in data collection and government officers often do not know how to approach persons with

³⁰ Six member DPOs: GERKATIN, BILIC, SEHATI, PERTUNI, SIGAB, and SAPDA

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²⁹ See GOI, 2016, p.41 – no disaggregated figures available

disabilities; and that government institutions are not aware about the importance of data on persons with disabilities for developing appropriate programmes. (Disability Convention Team, 2017)

National Intercensal Survey (SUPAS) 2015

The disability section of the 2015 SUPAS questionnaire consists of eight questions. The questions are based on the WG short set of question³¹ with additional questions and adapted multiple-choice answers. The questions are applied to the population aged two years and older: (National Institute of Statistics Indonesia, 2017, p. 161)

Table 13: SUPAS 2015 disability questionnaire 32

No	Question			Answers		
1	Does (NAME) have difficulty seeing?	Yes, cannot see at all.	Yes, a lot of difficulty.	Yes, some difficulty		No, no difficulty.
2	Does (NAME) have difficulty hearing?	Yes, cannot hear at all.	Yes, a lot of difficulty.	Yes, some difficulty		No, no difficulty.
3	Does (NAME) have difficulty walking or climbing stair?	Yes, needs full assistance by other people.	Yes, uses assistive device and needs help by others.	Yes, even when using assistive device.	Yes, not using assistive device.	No, no difficulty.
4	Does (NAME) have difficulty using hands or fingers?	Yes, cannot use hands or fingers.	Yes, a lot of difficulty.	Yes, some difficulty		No, no difficulty.
6	Does (NAME) have behavioural or emotional disorders?	Yes, always experiences difficulties.	Yes, often experiences difficulties.	Yes, experiences some difficulty		No, no difficulty.
7	Does (NAME) have difficulty speaking and / or understanding / communicating other people?	Yes, cannot not at all understand / be understood / communicate.	Yes, a lot of difficulty.	Yes, some difficulty		No, no difficulty.
8	Does (NAME) have difficulty with self-care (like washing, eating, dressing, defecating, urinating)?	Yes, cannot at all take care of itself.	Yes, a lot of difficulty.	Yes, some difficulty		No, no difficulty.

The final report on the data collection disaggregates the data on gender as well as urban and rural place of living. The report features national data and per province. (National

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³¹ See: Short Set of Questions

³² Translated by author

Institute of Statistics Indonesia, 2015, pp. 62-203) The report does features the raw data only and does not express statistical data in percentages.

GIZ programme initiatives

The GIZ Social Protection Programme (SPP) provides technical expertise, capacity development, process facilitation, and opportunities for South-South dialogue for the Ministry of National Development Planning (BAPPENAS) and the Ministry of Social Welfare (MoSA) in the intervention areas of social health insurance, inclusion of persons with disabilities, social assistance, and financial inclusion of persons with disabilities. (GIZ, 2017)

SPP receives data on persons with disabilities from MoSA. The publication 'Ministry of Social Welfare in Numbers' (Ministry of Social Welfare, 2012) does not explain how it collects or processes data, nor are any definitions stated.

Conclusion

The situation of quality data on persons with disabilities does unfortunately not feature any standardised tool that is based on international standards. Individual government institutions are gathering their own data with limited scope. Datasets of the institutions are not compatible and do not allow comparison. To improve the situation and provide quality data for the needs of SPP, Indonesia should adapt the methods of DHS or MICS.

Tanzania

UNCRPD

The Government of Tanzania (GOT) has ratified the UNCRPD on 10th November 2009. (OHCHR, 2017) No report of the GOT to the CRPD is available on the website of OHCHR³³.

Data

The Tanzania 2008 Disability Survey collected data on the population with a disability age 7 and above. The survey incorporates the WG short set of questions along additional question sets.

The results for the population age 7 to 19 years old are as followed in percent: (National Bureau of Statistics Tanzania, 2008, p. 44)

Table 14: Tanzania 2008 Disability Survey

			Tanz	ania	nia Mainlan			land	and Zanzibar						Total						
		Rural		l	Jrbar	า	ı	Rural		ι	Jrbar	1		Rura	l	l	Jrbar	า			
	М	F	т	M	F	т	М	F	т	M	F	т	М	F	т	М	F	т	М	F	т
7-9	3.0	2.6	2.8	5.4	1.6	3.6	2.9	2.6	2.8	5.5	1.6	3.7	4.6	2.2	3.5	3.2	1.7	2.3	3.6	2.4	3.0
10- 14	3.9	3.6	3.8	3.6	1.5	2.4	3.9	3.6	3.8	3.7	1.5	2.5	3.7	3.1	3.4	0.8	1.6	1.2	3.9	3.1	3.5
15- 19	4.0	3.0	3.5	3.1	6.2	4.7	4.0	2.9	3.5	2.9	6.4	4.8	2.0	5.7	3.9	7.5	1.6	4.1	3.7	3.9	3.8

GIZ programmes initiatives

GIZ is involved in Tanzania's development of the health through the *Tanzanian German Programme to Support Health* (TGPSH) since 25 years. TGPSH's mission is to deliver better services for better health in Tanzania. This shall be achieved by increasing (i) access to services for the poor, (ii) private investment in health, (iii) services for marginalized groups, (iv) district health management, (v) hospital management, and (vi) maternal and new-born care. (GIZ, 2016, p. 7)

³³ See http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

Since seven years a sub-program of TGPSH called *Improvement of Maternal and Child Health* (IMCH) focuses on capacity building and structural development of health care at regional and district level.³⁴ The *No Baby Left Out* initiative initiated by BMZ and GIZ focuses on on-the-job training for health personnel to achieve the reduction of newborn mortality rates. The initiative developed a *Newborn Triage Checklist*³⁵ to assess the newborn child (i) shortly after, (ii) 4-8 hours after birth, and (iii) within 20-24 hours after birth. The checklist provides spaces for taking down data on the (i) time of the assessment, temperature, respiration rate, feeding, movements, and weight. (GIZ, 2013)

Conclusion

For the purpose of improving maternal and child health, the DMAT approach of collecting data on children from age zero to six years old is very beneficial. Statistical data like for instance the WG questions are less beneficial for this purpose.

³⁴ Based on questioner and Skype conference call

³⁵ The Newborn Triage Checklist is accessible in annex 11

Conclusion and recommendations

Many countries have collected data on their population through censuses and surveys. Over the years the questionnaires have been expanded and adapted to new human rights standards enshrined in the UNCRC and UNCRPD. However, data on children with disabilities is still scattered and not collected in a coherent manner. (UNICEF, 2013, pp. 63-68) Children are overlooked if surveys are not target towards them. Children with intersecting risks of exclusion like children with disabilities from a low socio-economic background or girls with disabilities are at even higher risk to be overseen. (UNESCO, 2015, pp. 22-27). Surveys that feature questionnaires that target children³⁶ have the potential to generate better results on the situation of children with disabilities. (Washington Group on Disability Statistics, 2017) (Cappa, Collecting Data on Child Disability, 2014).

Collecting data on children relies on the responses by proxies, which are usually their parents or caregivers. Since surveys and censuses are designed to be self-reporting tools, many parents and caregivers might face challenges to correctly report due to a lack of knowledge on norms, standards, expectations about child development, children's rights, etc. Even though parents and caregivers are in many cases very well aware of the challenges and functional limitations their children face, they might not correctly report back in censuses and surveys. This dilemma becomes even bigger when it comes to collecting data on children below the age of two years old as they in all cases rely on the answers of proxies.

³⁶ See section on WG Child Functioning Module

Table 15: Tools for project level

Tool	Methodology	Description	Adv	vantages	Dis	advantage
Washing Group Disability Questions for adults and children	Functional assessment Ideal for surveys and censuses.	Sets of questions to be added to population censuses or surveys to collect data on disability. Each set has been designed to identify those who are at greater risk than the general population for participation restrictions because of the presence of difficulties. The WG provides questions sets for children age 2-4 years old (16 questions), children 5-17 years old (24 questions) and adults (6 or 37 questions).	 2. 3. 4. 	Adult short set questionnaire (6 questions) can be easily inserted in existing surveys and censuses. Deliver internationally comparable data. Takes the presence of assistive devices into account Allows to develop a graph with the continuum of disability*	 2. 3. 	'Some difficulty', 'a lot of difficulty' depends very much on personal perception / expectations and is very challenging to standardise. Child questionnaires have many questions The phrase 'compare to children of the same age' can lead to misleading results as not all children develop at the same speed. Do not capture children until the age of two years old.
Physical Screening Tools for children below 6	Medical assessment by nurse, midwife, later confirmed by medical doctor trained on referral pathways and service delivery directory Ideal in medical setting for early identification and intervention of children with disabilities	Two medical tools for early detection and early intervention: neonate and 1-60 months. A medical body check is conducted, focussing on the identification of potential physical and sensorial impairments Positively screened by nurses and midwives are referred to a doctor at the Referral hospital to confirm impairment and professionally refer for further diagnosis / intervention	1.	Captures children age up until the age of six years old. Physical screening tool facilitates early detection, triggers early referral, medical diagnosis and early medical / physical rehab interventions (secondary and tertiary prevention).	 1. 2. 3. 4. 5. 	Based on medical model: fixing the individual by medical or physical rehab intervention. Only trained medical personnel can make the assessment Does not capture functional limitations that are the result of impairments. No continuum of disabilities Does not deliver population data.

Developmental	Functional assessment	Tool to monitor a child's development and	1.	For children up until age six years old.	1.	, ,
milestones assessment tools (DMAT) for children below 6	Ideal in health and (pre-) school settings for early identification and intervention of children with disabilities	detect developmental delays. Milestones are age-specific achievements an average child can be expected to demonstrate. Normally, different domains are taken into consideration (i.e. motor, social and language / cognitive skills). FULL DMAT = 136-140 culturally appropriate milestones Community-Based DMAT = 4 age-specific milestone performance questions indicating developmental delays, triggering referral for full DMAT for children of 9m, 18m, 24m, 36m, 48m and 60m	 3. 4. 7. 8. 	Set a cultural-specific benchmark for child development which can be used as a reference (rather than obtaining subjective impression of caretakers) Can be used to identify children at risk for disabilities Culturally appropriate research leads to development reference charts / benchmarks Linked to early intervention (development stimulation exercises) Can be used for children below 2 years CB-DMAT is fast (2 min), ideal for screening purposes with the possibility to control the number of referrals by changing delay trigger (P90% vs P100% of month cohort) CB-DMAT can be administered in CBR programmes. Delays trigger medical assessment and treatment / stimulation exercises (rehab)	3.4.5.6.	the stimulations in the environment and the child's personality (urban faster than rural children) School enrolment is confounding factor for many milestones Resource intensive as initial research needs to be carried out to establish local reference charts for developmental milestone performance references Full DMAT is time consuming (20-3 min): physiotherapist or (pre-) school teacher No continuum of disabilities Do not deliver population data. Must be culturally adapted.
WHODAS 2.0	Functional assessment for adults Ideal for disability specific surveys and censuses.	Assessment tool that measures health and disability over 6 domains: i. cognition, ii. mobility, iii. self-care, iv. getting along, v. life activities, and vi. participation.	 2. 3. 4. 	Based on ICF = social model Measures impact of disability on quality of life / possibility to participate Measures indirectly the impact of the (barrier-free) environment and of personal factors Disability spectrum: Population data when random sampling is applied (all persons included) allowing to differentiate between people with and without certain types of disabilities	 2. 3. 4. 	No module for children (<18 years 'Some difficulty', 'a lot of difficulty depends very much on personal perception / expectations and is very challenging to standardise. Resource intensive (funding, personnel, time,), especially when random sampling is applied No identification / selection mechanism to include only person with disabilities. 'Moderate', 'Severe' depends very much on personal perception /

expectations and is very challenging to standardise.

Table 16: Data sources for country level and multi-sectoral programmes

Tool	Methodology	Description	Advantages	Disadvantage
Multi Indicator Cluster Survey (MICS)	Population survey. Includes functional assessment for children age 2 and above.	Population survey that features module on disability using the WG questions. Modules for children aged 2-4 years old and aged 5-17 years old are available.	Delivers internationally comparable data.	See table before comments: on 'Washing Group Disability Questions for adults and children'
Demographic Health Survey (DHS)	Population survey. Includes functional assessment for children (age 5-17 years old) and adults.	Population survey that features module on disability using the WG questions.	Delivers internationally comparable data.	See table before: comments on 'Washing Group Disability Questions for adults and children'
Model Disability Survey (MDS)	Population survey with special focus on adult persons with disabilities. Includes functional assessment for adults.	Population survey based on ICF. Only for adults age 18 and above.	 Based on ICF = social model Measures impact of disability on quality of life / possibility to participate Measures indirectly the impact of the (barrier-free) environment and of personal factors Disability spectrum Population data when random sampling is applied (all persons included) allowing to differentiate between people with and without certain types of disabilities 	No module for children yet.

^{*} The ICF is universal because it covers all human functioning and <u>treats disability as a continuum</u> rather than categorizing people with disabilities as a separate group: disability is a matter of more or less, not yes or no. However, policy-making and service delivery might require thresholds to be set for impairment severity, activity limitations, or participation restriction. (

Which tool to use – the WG questions, a DMAT approach or another tool – depends very much on the nature of the project and the goals it wants to achieve. It is therefore important to analyse the purpose of the data needs to be gathered. If the purpose is clear, one can start to choose a suitable tool and methodology to collect data.

Muskoka in Cambodia and IMCH in Tanzania focus on maternal and child health and develop interventions and programmes to improve the situation of mothers and children. Both projects are located in the medical sector and improve the situation of newborns. DMATs and functional assessment tools are a good choice for this purpose. Datasets based on WG questions are a second choice. Culturally adapted DMATs and physical screening protocols that trigger early intervention where necessary are much more useful for children and parents.

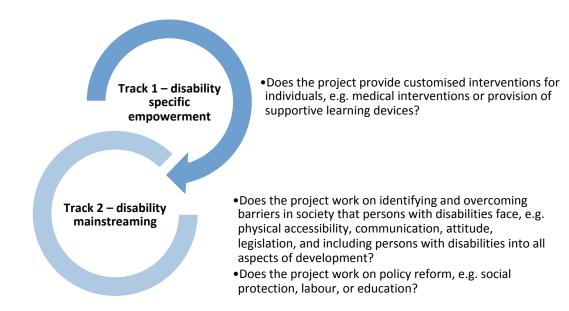
The GIZ SPP in Indonesia has a slightly different focus. It looks at improving the social security system and making it more inclusive of persons with disabilities. The approach is to give technical advice to BAPPENAS and MoSA. Here quality statistical data based on tools using WG questions would be a great asset to support the GOI in developing more efficient social security interventions. However, when it comes to the direct identification of children with disabilities and verification if they are eligible for social protection other tools and methodologies are appropriate. First, DMATs are the right tool to identify children with disabilities and assess their functional limitations. Secondly, administrative data from schools and civil registration offices can be assessed to crosscheck if all children are in school. Children with disabilities are very often not enrolled in education and do not attend schools and are therefore easy to be identified.

Programmes that are not sure which data would be more beneficial can access their needs using the twin-track-approach to disability.

Twin-Track Approach

Projects and interventions can use the Twin-Track Approach model to assess which kind of data they need to achieve their goals.

Figure 12: Twin-Track Approach



DMATs and physical screening tools will deliver data which is more useful if the project is closer to track one of the Twin-Track Approach. DMAT results give the project the opportunity to produce customised and individual solutions to overcome barriers and increase the participation and wellbeing of a child.

Should the project work more on disability mainstreaming in society (track 2) than statistical data like WG questions, WHODAS 2.0, DHS and MICS are more useful.

Annexes

Annex 1 – Example ICF use

Figure 13: ICF example 1

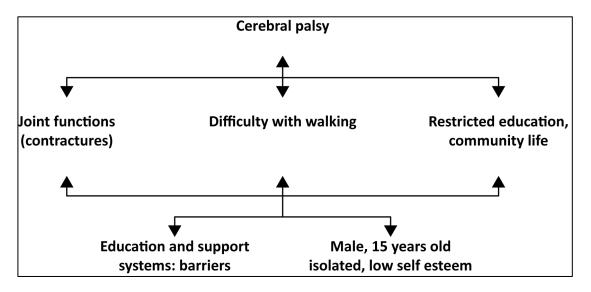


Figure 14: ICF example 2

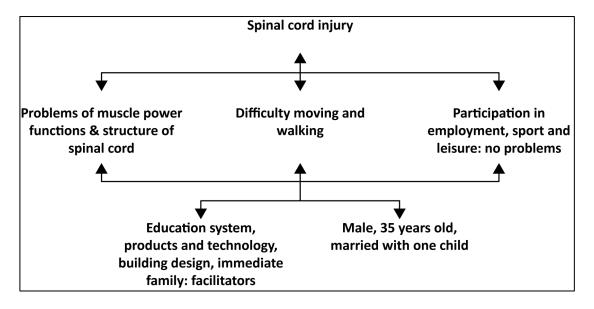
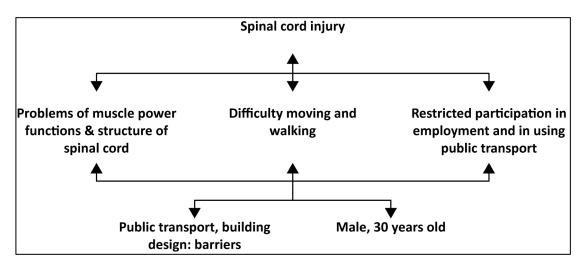


Figure 15: ICF example 3



Annex 2 - WG Short set of Questions

The Washington Group Short Set of Questions on Disability

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

- 1. Do you have difficulty seeing, even if wearing glasses?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all
- 2. Do you have difficulty hearing, even if using a hearing aid?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all
- 3. Do you have difficulty walking or climbing steps?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all
- 4. Do you have difficulty remembering or concentrating?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all
- 5. Do you have difficulty (with self-care such as) washing all over or dressing?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all
- 6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
 - a. No no difficulty
 - b. Yes some difficulty
 - c. Yes a lot of difficulty
 - d. Cannot do at all

1

Washington Group - Extended Question Set on Functioning (WG ES-F)

(Version 9 November 2011)

(Proposal endorsed at the joint Washington Group / Budapest Initiative Task Force Meeting, 3-5 November 2010, Luxembourg)

Preamble to the WG ES-F:

Text provided in [] may be used at the discretion of the country / survey organization.

Interviewer, read: "Now I am going to ask you some [additional] questions about your ability to do different activities, and how you have been feeling. [Although some of these questions may seem similar to ones you have already answered, it is important that we ask them all.]"

VISION

VIS 1 [Do/Does] [you/he/she] wear glasses?

- 1. Yes
- 2. No
- 7. Refused
- 9. Don't know

	[Do/Does] [you/he/she] have difficulty seeing, [If VIS_1 = 1: even when
VIS_2	wearing
	[your/his/her] glasses]? Would you say [Read response categories]
	1. No difficulty
	2. Some difficulty
	3. A lot of difficulty
	4. Cannot do at all / Unable to do
	7. Refused
	9. Don't know

[Note: This item is Question 1 in the WG Short Set.]

<u>OPTIONAL</u> Vision questions:

VIS_3	[Do/does] [you/he/she] have difficulty clearly seeing someone's face across a						
	room [$If VIS_1 = 1$: even when wearing [your/his/her] glasses]? Would you						
	say [Read response categories]						
	1. No difficulty						
	2. Some difficulty						
	3. A lot of difficulty						
	4. Cannot do at all / Unable to do						
	7. Refused						
	9. Don't know						
VIS_4	[Do/does] [you/he/she] have difficulty clearly seeing the picture on a coin [If						
	$VIS_1 = 1$: even when wearing [your/his/her] glasses]? Would you say [Read						
	response categories]?						
	1. No difficulty						
	2. Some difficulty						
	3. A lot of difficulty						
	4. Cannot do at all / Unable to do						
	7. Refused						
	9. Don't know						
	[Note: Countries may choose to replace "the picture of a coin" with an						
	equivalent item.]						

	HEARING					
HEAR_1	[Do/Does] [you/he/she] use a hearing aid?					
	1. Yes					
	2. No					
	7. Refused					
	9. Don't know					

- HEAR_2 [Do/Does] [you/he/she] have difficulty hearing, [If HEAR_1 = 1: even when using a hearing aid(s)]? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

[Note: This item is Question 2 in the WG Short Set.]

OPTIONAL Hearing questions:

- HEAR_3 How often [do/does] [you/he/she] use [your/his/her] hearing aid(s)? Would you say... [Read response categories]
 - 1. All of the time
 - 2. Some of the time
 - 3. Rarely
 - 4. Never
 - 7. Refused
 - 9. Don't know
- HEAR_4 [Do/does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a quiet room [If HEAR_1 = 1: even when using [your/his/her] hearing aid(s)]? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know
- HEAR_5 [Do/does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a noisier room [If HEAR_1 = 1: even when using [your/his/her] hearing aid(s)]? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

MOBILITY

- MOB_1 [Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say... [*Read response categories*]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 9. Refused
 - 9. Don't know

[Note: This item is Question 3 in the WG Short Set.]

- MOB_2 [Do/does] [you/he/she] use any equipment or receive help for getting around?
 - 1. Yes

2. No (*Skip to MOB 4.*)

7. Refused (Skip to MOB_4.)

9. Don't know (Skip to MOB_4)

MOB_3 [Do/does] [you/he/she] use any of the following?

Interviewer: Read the following list and record all affirmative responses:

		1. Yes	2. No	7. Refused	9 Don't Know
A.	Cane or walking stick?				
B.	Walker or Zimmer frame?				
C.	Crutches?				
D.	Wheelchair or scooter?				
E.	Artificial limb (leg/foot)?				
F.	Someone's assistance?				
G.	Other (please specify):				

- MOB_4 [Do/Does] [you/he/she] have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [*If MOB_2 = 1*: without the use of [your/his/her] aid]? Would you say... [*Read response categories*]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do (Skip to MOB 6)
 - 7. Refused
 - 9. Don't know

[Note: Allow national equivalents for 100 metres.]

- MOB_5 [Do/Does] [you/he/she] have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [*If MOB_2 = 1*: without the use of [your/his/her] aid]? Would you say... [*Read response categories*]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

[Note: Allow national equivalents for 500 metres.]

- MOB_6 [Do/Does] [you/he/she] have difficulty walking up or down 12 steps? Would you say... [*Read response categories*]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

If $MOB_2 = 2$ "No", skip to next section. If $MOB_3 = D$ "Wheelchair", skip to next section.

- MOB_7 [Do/Does] [you/he/she] have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using [your/his/her] aid? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do (skip MOB 8)
 - 7. Refused
 - 9. Don't know
- MOB_8 [Do/Does] [you/he/she] have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using [your/his/her] aid? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

COMMUNICATION

- COM_1 Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

[Note: This item is Question 6 in the WG Short Set.]

- COM 2 [Do/does] [you/he/she] use sign language?
 - 1. Yes
 - 2. No
 - 7. Refused
 - 9. Don't know

COGNITION (REMEMBERING)

- COG_1 [Do/does] [you/he/she] have difficulty remembering or concentrating? Would you say... [Read response categories]
 - 1. No difficulty
 - 2. Some difficulty
 - 3. A lot of difficulty
 - 4. Cannot do at all / Unable to do
 - 7. Refused
 - 9. Don't know

[Note: This item is Question 4 in the WG Short Set.]

OPTIONAL Cognition questions:

- COG_2 [Do/does] [you/he/she] have difficulty remembering, concentrating, or both? Would you say... [Read response categories]
 - 1. Difficulty remembering only
 - 2. Difficulty concentrating only (*skip to next section*)
 - 1. Difficulty with both remembering and concentrating
 - 7. Refused
 - 9. Don't know
- COG_3 How often [do/does] [you/he/she] have difficulty remembering? Would you say... [Read response categories]
 - 1. Sometimes
 - 2. Often
 - 3. All of the time
 - 7. Refused
 - 9. Don't know
- COG_4 [Do/does] [you/he/she] have difficulty remembering a few things, a lot of things, or almost everything? Would you say... [Read response categories]
 - 1. A few things
 - 2. A lot of things
 - 3. Almost everything
 - 7. Refused
 - 9. Don't know

Please see the following webpage for more information about the Washington Group on Disability Statistics: http://www.cdc.gov/nchs/washington_group.htm.

	SELF-CARE					
SC_1	[Do/does] [you/he/she] have difficulty with self care, such as washing all over or					
	dressing? Would you say [Read response categories]					
	1. No difficulty					
	2. Some difficulty					
	3. A lot of difficulty					
	4. Cannot do at all / Unable to do					
	7. Refused					
	9. Don't know					
	[Note: This item is Question 5 in the WG Short Set.]					

	UPPER BODY					
UB_1	[Do/Does] [you/he/she] have difficulty raising a 2 liter bottle of water or soda from					
	waist to eye level? Would you say [Read response categories]					
	1. No difficulty					
	2. Some difficulty					
	3. A lot of difficulty					
	4. Cannot do at all / Unable to do					
	7. Refused					
	9. Don't know					
UB_2	[Do/Does] [you/he/she] have difficulty using [your/his/her] hands and fingers, such					
	as picking up small objects, for example, a button or pencil, or opening or closing					
	containers or bottles? Would you say [Read response categories]					
	1. No difficulty					
	2. Some difficulty					
	3. A lot of difficulty					
	4. Cannot do at all / Unable to do					
	7. Refused					
	9. Don't know					

AFFECT (ANXIETY AND DEPRESSION)

Proxy respondents may be omitted from this section, at country's discretion.

Interviewer: If respondent asks whether they are to answer about their emotional states after taking mood-regulating medications, say: "Please answer according to whatever medication [you were/he was/she was] taking."

- ANX_1 How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say... [*Read response categories*]
 - 1. Daily
 - 2. Weekly
 - 3. Monthly
 - 4. A few times a year
 - 5. Never
 - 7. Refused
 - 9. Don't know
- ANX_2 [Do/Does] [you/he/she] take medication for these feelings?
 - 1. Yes
 - 2. No (If "Never" to ANX 1 and "No" to ANX 2, skip to DEP 1.)
 - 7. Refused
 - 9. Don't know
- ANX_3 Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would [you/he/she] say... [Read response categories]
 - 1. A little
 - 2. A lot
 - 3. Somewhere in between a little and a lot
 - 7. Refused
 - 9. Don't know

- DEP_1 How often [do/does] [you/he/she] feel depressed? Would [you/he/she] say... [Read response categories]
 - 1. Daily
 - 2. Weekly
 - 3. Monthly
 - 4. A few times a year
 - 5. Never
 - 7. Refused
 - 9. Don't know
- DEP 2 [Do/Does] [you/he/she] take medication for depression?
 - 1. Yes
 - 2. No (If "Never" to DEP_1 and "No" to DEP_2, skip to next section.)
 - 7. Refused
 - 9. Don't know
- DEP_3 Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say... [Read response categories]
 - 1. A little
 - 2. A lot
 - 3. Somewhere in between a little and a lot
 - 7. Refused
 - 9. Don't know

PAIN

Proxy respondents may be omitted from this section, at country's discretion.

Interviewer: If respondent asks whether they are to answer about their pain when taking their medications, say: "Please answer according to whatever medication [you were/he was/she was] taking."

- PAIN_1 In the past 3 months, how often did [you/he/she] have pain? Would you say... [Read response categories]
 - 1. Never (If "Never" to PAIN 1, skip to next section.)
 - 2. Some days
 - 3. Most days
 - 4. Every day
 - 7. Refused
 - 9. Don't know

- PAIN_2 Thinking about the last time [you/he/she] had pain, how much pain did [you/he/she] have? Would you say... [Read response categories]
 - 1. A little
 - 2. A lot
 - 3. Somewhere in between a little and a lot
 - 7. Refused
 - 9. Don't know

FATIGUE

Proxy respondents may be omitted from this section, at country's discretion.

- TIRED_1 In the past 3 months, how often did [you/he/she] feel very tired or exhausted? Would you say... [Read response categories]
 - 1. Never (If "Never" to TIRED 1, skip to next section.)
 - 2. Some days
 - 3. Most days
 - 4. Every day
 - 7. Refused
 - 9. Don't know
- TIRED_2 Thinking about the last time [you/he/she] felt very tired or exhausted, how long did it last? Would you say... [Read response categories]
 - 1. Some of the day
 - 2. Most of the day
 - 3. All of the day
 - 7. Refused
 - 9. Don't know
- TIRED_3 Thinking about the last time [you/he/she] felt this way, how would you describe the level of tiredness? Would you say... [Read response categories]
 - 1. A little
 - 2. A lot
 - 3. Somewhere in between a little and a lot
 - 7. Refused
 - 9. Don't know

Annex 4 – WG Child Functioning Age 2 to 4 years old

	113 Old	1
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (name) WEAR GLASSES?	Yes 1 No 2	2⇔CF3
DOES (name) WEAR GLASSES:	NU Z	Z-> CF3
CF2. WHEN WEARING HIS/HER GLASSES, DOES (name) HAVE DIFFICULTY SEEING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CF4 2⇔CF4 3⇔CF4 4⇔CF4
CF3. DOES (name) HAVE DIFFICULTY SEEING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF4. DOES (name) USE A HEARING AID?	Yes 1 No 2	2⇔CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (name) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CF7 2⇔CF7 3⇔CF7 4⇔CF7
CF6. DOES (name) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF7. DOES (name) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes 1 No 2	2⇔CF10
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING? WOULD YOU SAY (name) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty 2 A lot of difficult 3 Cannot do at all 4	2 / 01 10
CF9. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇒CF11 2⇒CF11 3⇒CF11 4⇒CF11
CF10. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF11 . COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND?	No difficulty	

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	
CF12. DOES (name) HAVE DIFFICULTY UNDERSTANDING YOU?	No difficulty 1
WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty 2 A lot of difficult 3 Cannot do at all 4
CF13. WHEN (name) SPEAKS, DO YOU HAVE DIFFICULTY UNDERSTANDING HIM/HER?	
WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty
CF14. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY LEARNING THINGS?	No difficulty 1 Some difficulty 2
WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	A lot of difficult 3 Cannot do at all 4
CF15. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY PLAYING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty
CF16. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES (name) KICK, BITE OR HIT OTHER CHILDREN OR ADULTS? WOULD YOU SAY: NOT AT ALL, THE SAME OR LESS, MORE	Not at all
OR A LOT MORE?	A lot more 4

Annex 5 – WG Child Functioning Age 5 to 17 years old

	I	1
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (name) WEAR GLASSES?	Yes 1 No 2	2⇔CF3
CF2. WHEN WEARING HIS/HER GLASSES, DOES (name) HAVE DIFFICULTY SEEING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CF4 2⇔CF4 3⇔CF4 4⇔CF4
CF3. DOES (name) HAVE DIFFICULTY SEEING? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF4. DOES (name) USE A HEARING AID?	No difficulty	2⇒CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (name) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇒CF7 2⇒CF7 3⇒CF7 4⇒CF7
CF6. DOES (name) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF7. DOES (name) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes 1 No 2	2⇔CF12
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (name) HAS: SOME DIFFICULTY, A LOT OF	Some difficulty 2 A lot of difficult 3	3⇔CF10
CF9. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].	Cannot do at all 4	4⇔CF10
WOULD YOU SAY (name) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty	220544
CF10. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES	Some difficulty 2	3⇒CF14

(name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].	A lot of difficult 3 Cannot do at all 4	4⇔CF14
WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?		
CF11 . WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].	No difficulty 1	1⇔CF14
WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty 2 A lot of difficult 3 Cannot do at all 4	
CF12. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].	No difficulty 1	
WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty 2 A lot of difficult 3 Cannot do at all 4	3⇒CF14 4⇒CF14
CF13. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT		
COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF14. DOES (name) HAVE DIFFICULTY WITH SELF- CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF15. WHEN (name) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CF16. WHEN (name) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF THIS HOUSEHOLD? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	

CF17. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY LEARNING THINGS? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF18. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY REMEMBERING THINGS? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF19. DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF19. DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF19. DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF19. DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF19. DOES (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF20. DOES (name) HAVE DIFFICULTY ACCEPTING CHANGES IN HIS/HER ROUTINE? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF21. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF22. DOES (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF22. DOES (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF22. DOES (name) HAVE DIFFICULTY OR CANNOT DO AT ALL? CF23. HOW OFTEN DOES (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF24. HOW OFTEN DOES (name) SEEM VERY ANXIOUS, NERVOUS OR WORRIED? WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF23. HOW OFTEN DOES (name) SEEM VERY SAD OR DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF24. HOW OFTEN DOES (name) SEEM VERY SAD OR DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF24. HOW OFTEN DOES (name) SEEM VERY SAD OR DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? CF24. HOW OFTEN DOES (name) SEEM VERY SAD OR DIFFICULTY OR CANNOT DO AT ALL? CF25. HOW OFTEN DOES (name) SEEM VERY SAD OR DIFFICULTY, A LOT OF DIFFICULTY OR CANNOTHLY, A FEW TIMES A YEAR OR NEVER?		
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Annex 6 – MICS questionnaire for children under five, section on child functioning

The table below shows the original MICS questioner with a complementary column on the right referring to the corresponding question in the WG child functioning questions for children age 2 to 4 (see annex 4)

CHILD FUNCTIONING		UCF	Based on WG
UCF1. Check UB2: Child's age?	AGE 0 OR 1 1 AGE 2, 3 OR 4 2	1 <i>⇒End</i>	
UCF2. I would like to ask you some questions about difficulties (<i>name</i>) may have.	YES		CF1
Does (name) wear glasses?			
UCF3. Does (name) use a hearing aid?	YES		CF4
UCF4. Does (<i>name</i>) use any equipment or receive assistance for walking?	YES		CF7
UCF5. In the following questions, I will ask you to answer by selecting one of four possible answers. For each question, would you say that (name) has: 1) no difficulty, 2) some difficulty, 3) a lot of difficulty, or 4) that (he/she) cannot at all. Repeat the categories during the individual questions whenever the respondent does not use an answer category: REMEMBER THE FOUR POSSIBLE ANSWERS: WOULD YOU SAY THAT (NAME) HAS: 1) NO DIFFICULTY, 2) SOME DIFFICULTY, 3) A LOT OF DIFFICULTY, OR 4) THAT (HE/SHE) CANNOT AT ALL?	NO DIFFICULTY		
UCF6. Check UCF2: Child wears glasses?	YES, UCF2=1	1 <i>⇒UCF7A</i> 2 <i>⇒UCF7B</i>	
UCF7A. When wearing (his/her) glasses, does (<i>name</i>) have difficulty seeing?UCF7B. Does (<i>name</i>) have difficulty seeing?	NO DIFFICULTY		CF2
UCF8. Check UCF3: Child uses a hearing aid?	YES, UCF3=1	1 <i>⇒UCF9A</i> 2 <i>⇒UCF9B</i>	

UCF9A. When using (his/her) hearing aid(s), does (<i>name</i>) have difficulty hearing sounds like peoples' voices or music?	NO DIFFICULTY		CF5
UCF9B . Does (<i>name</i>) have difficulty hearing sounds like peoples' voices or music?	CANNOT HEAR AT ALL 4		CF6
UCF10. Check UCF4: Child uses equipment or receives assistance for walking?	YES, UCF4=1	1 <i>⇒UCF11</i> 2 <i>⇒UCF13</i>	
UCF11. Without (his/her) equipment or assistance, does (<i>name</i>) have difficulty walking?	SOME DIFFICULTY		CF8
UCF12. With (his/her) equipment or assistance, does (<i>name</i>) have difficulty walking?	NO DIFFICULTY	1 <i>⇒UCF14</i> 2 <i>⇒UCF14</i> 3 <i>⇒UCF14</i> 4 <i>⇒UCF14</i>	CF 9
UCF13. Compared with children of the same age, does (<i>name</i>) have difficulty walking?	NO DIFFICULTY		CF10
UCF14. Compared with children of the same age, does (<i>name</i>) have difficulty picking up small objects with (his/her) hand?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT PICK UP AT ALL 4		CF11
UCF15. Does (<i>name</i>) have difficulty understanding you?	NO DIFFICULTY		CF12
UCF16. When (<i>name</i>) speaks, do you have difficulty understanding (him/her)?	NO DIFFICULTY		CF13
UCF17. Compared with children of the same age, does (<i>name</i>) have difficulty learning things?	NO DIFFICULTY		CF14
UCF18. Compared with children of the same age, does (<i>name</i>) have difficulty playing?	NO DIFFICULTY		CF15

UCF19. The next question has five different options for answers. I am going to read these to you after the question.		CF19
Compared with children of the same age, how much does (<i>name</i>) kick, bite or hit other children or adults?	NOT AT ALL	
Would you say: not at all, less, the same, more or a lot more?	MORE 4 A LOT MORE 5	

Annex 7 – MICS questionnaire for children age 5-17, section on child functioning

The table below shows the original MICS questionnaire with a complementary column on the right referring to the corresponding question in the WG child functioning questions for children age 5 to 17 (see annex 5)

CHILD FUNCTIONING	FCF		
FCF1 . I would like to ask you some questions about difficulties (<i>name</i>) may have. Does (<i>name</i>) wear glasses or contact lenses?	YES		CF1
FCF2. Does (<i>name</i>) use a hearing aid?	YES		CF4
FCF3. Does (<i>name</i>) use any equipment or receive assistance for walking?	YES		CF7
FCF4. In the following questions, I will ask you to answer by selecting one of four possible answers. For each question, would you say that (name) has: 1) no difficulty, 2) some difficulty, 3) a lot of difficulty, or 4) that (he/she) cannot at all. Repeat the categories during the individual questions whenever the respondent does not use an answer category	NO DIFFICULTY		
FCF5. Check FCF1: Child wears glasses or contact lenses?	YES, FCF1=1	1 <i>⇒FCF6A</i> 2 <i>⇒FCF6B</i>	
FCF6A. When wearing (his/her) glasses or contact lenses, does (name) have difficulty seeing? FCF6B. Does (name) have difficulty seeing?	NO DIFFICULTY		CF2
FCF7. Check FCF2: Child uses a hearing aid?	YES, FCF2=1	1 <i>⇒FCF8A</i> 2 <i>⇒FCF8B</i>	
FCF8A. When using (his/her) hearing aid(s), does (name) have difficulty hearing sounds like peoples' voices or music? FCF8B. Does (name) have difficulty hearing sounds like peoples' voices or music?	NO DIFFICULTY		CF5
FCF9. Check FCF3: Child uses equipment or receives assistance for walking?	YES, FCF3=1 1 NO, FCF3=2 2	2 <i>⊳FCF14</i>	_

FCF10. Without (his/her) equipment or assistance, does (<i>name</i>) have difficulty	SOME DIFFICULTY2		CF8
walking 100 meters/yards on level ground? Probe: That would be about the length of 1 football field. Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.	A LOT OF DIFFICULTY	3 <i>⇒FCF12</i> 4 <i>⇒FCF12</i>	
FCF11. Without (his/her) equipment or assistance, does (name) have difficulty walking 500 meters/yards on level ground? Probe: That would be about the length of 5 football fields. Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.	SOME DIFFICULTY		CF9
FCF12. With (his/her) equipment or assistance, does (<i>name</i>) have difficulty walking 100 meters/yards on level ground? Probe: That would be about the length of 1 football field.	NO DIFFICULTY	3 <i>⇒FCF16</i> 4 <i>⇒FCF16</i>	CF10
FCF13. With (his/her) equipment or assistance, does (<i>name</i>) have difficulty walking 500 meters/yards on level ground? Probe: That would be about the length of 5 football fields.	NO DIFFICULTY	1 <i>⇒FCF16</i>	CF11
FCF14. Compared with children of the same age, does (<i>name</i>) have difficulty walking 100 meters/yards on level ground? Probe: That would be about the length of 1 football field.	NO DIFFICULTY	3 <i>⇒FCF16</i> 4 <i>⇒FCF16</i>	CF12
FCF15. Compared with children of the same age, does (<i>name</i>) have difficulty walking 500 meters/yards on level ground? Probe: That would be about the length of 5 football fields.	NO DIFFICULTY		CF13
FCF16. Does (<i>name</i>) have difficulty with self-care such as feeding or dressing (himself/herself)?	NO DIFFICULTY		CF14
FCF17. When (<i>name</i>) speaks, does (he/she) have difficulty being understood by people inside of this household?	NO DIFFICULTY		CF15

ECE10 WI	NO DIFFICULTIV	CE16
FCF18 . When (<i>name</i>) speaks, does (he/she) have difficulty being understood by people outside of this household?	NO DIFFICULTY	CF16
FCF19 . Compared with children of the same age, does (<i>name</i>) have difficulty learning things?	NO DIFFICULTY	CF17
FCF20 . Compared with children of the same age, does (<i>name</i>) have difficulty remembering things?	NO DIFFICULTY	CF18
FCF21. Does (<i>name</i>) have difficulty concentrating on an activity that (he/she) enjoys doing?	NO DIFFICULTY	CF19
FCF22. Does (<i>name</i>) have difficulty accepting changes in (his/her) routine?	NO DIFFICULTY	CF20
FCF23. Compared with children of the same age, does (<i>name</i>) have difficulty controlling (his/her) behaviour?	NO DIFFICULTY	CF21
FCF24. Does (<i>name</i>) have difficulty making friends?	NO DIFFICULTY	CF22
FCF25. The next questions have different options for answers. I am going to read these to you after each question. I would like to know how often (name) seems very anxious, nervous or worried. Would you say: daily, weekly, monthly, a few times a year or never?	DAILY 1 WEEKLY 2 MONTHLY 3 A FEW TIMES A YEAR 4 NEVER 5	CF23
FCF26. I would also like to know how often (name) seems very sad or depressed. Would you say: daily, weekly, monthly, a few times a year or never?	DAILY 1 WEEKLY 2 MONTHLY 3 A FEW TIMES A YEAR 4 NEVER 5	CF24

Annex 8 – Questionnaire

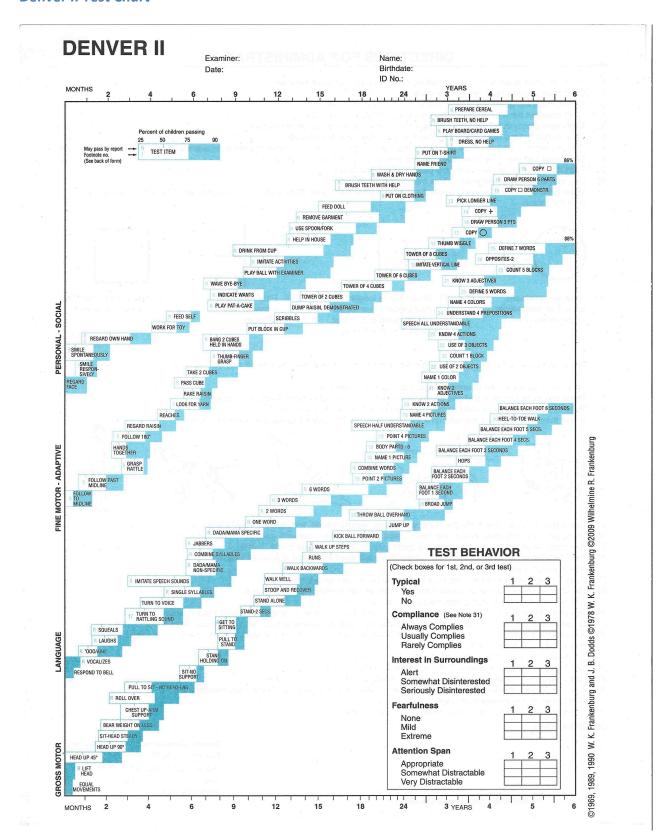
Questionnaire Data on children with disabilities

	Question	Answer
		General information
>	What is your name and position?	
>	Please describe briefly the project(s) you are currently working on?	
>	In which country is your project located?	
		Data Sources
>	Are persons with disabilities part of the target group (direct or potentially indirect) of your programme?	
>	For what purpose do you need disability data in general and data on children with disabilities in particular?	
>	Do you have access to data on children with disabilities?	
>	Please name the sources	
>	Which of the data sources do you find useful? Please explain your answer briefly. Thank you.	
>	Are you aware of the United Nations Washington Group (UN-WG) questions and the WHO International Classification of Functioning, Disability and Health (WHO-ICF)?	
>	Do you think that the data sources you are using incorporate the philosophy of the UN-WG or WHO-ICF?	

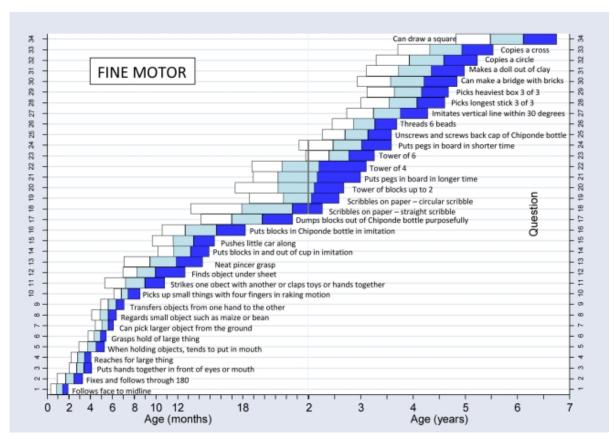
>	Do the data sources you are using give you satisfactory information for your work? Please explain. Thank you.	
>	What are the shortcomings of the data you are using? Please explain. Thank you.	
>	What kind data and information are you missing in the data sources that you access?	
		Collecting Data
>	Has your project made an effort to collect data?	
>	If yes, does the data collection include data on children with disabilities?	
>	Please describe the approach to data collection.	
>	What challenges did you face?	
>	Please send the data sources or links to data sources to alex@alexanderhauschild.com	

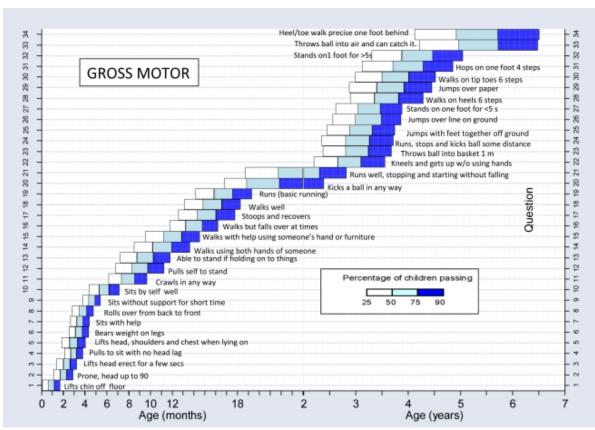
Annex 9 – DMAT performance charts with age-windows

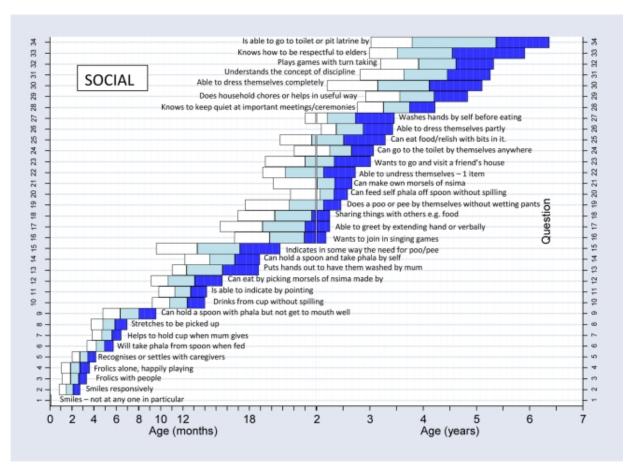
Denver II Test Chart

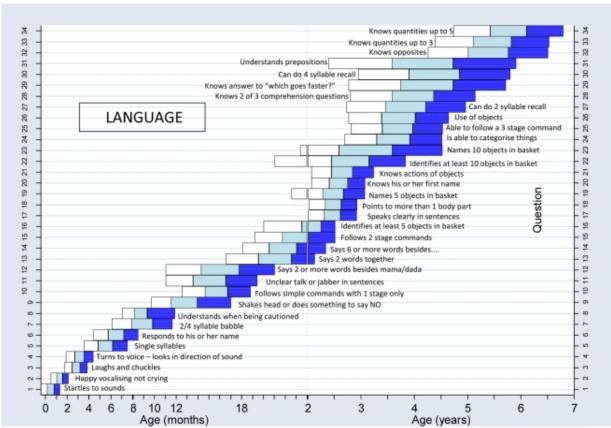


Malawi DMAT performance charts

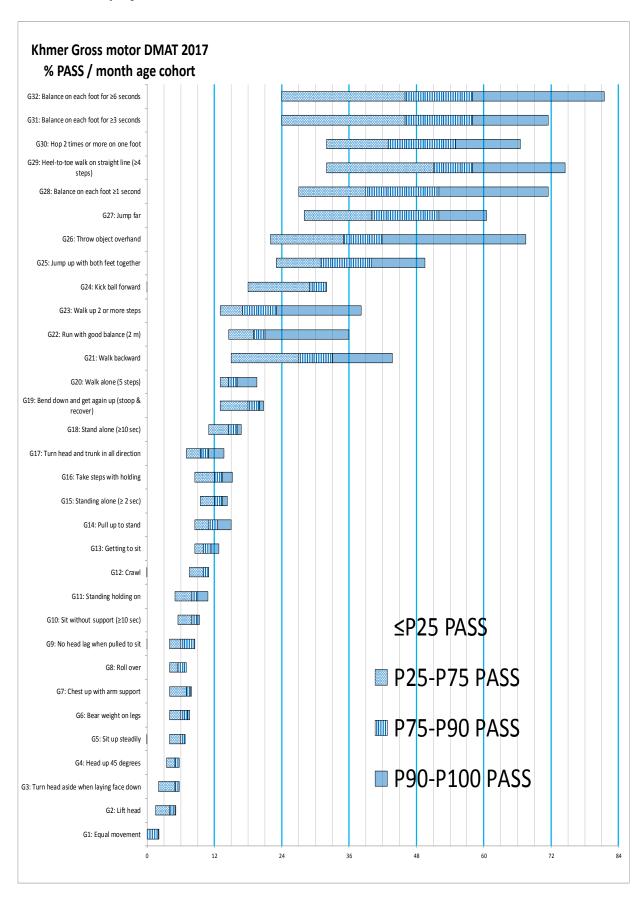


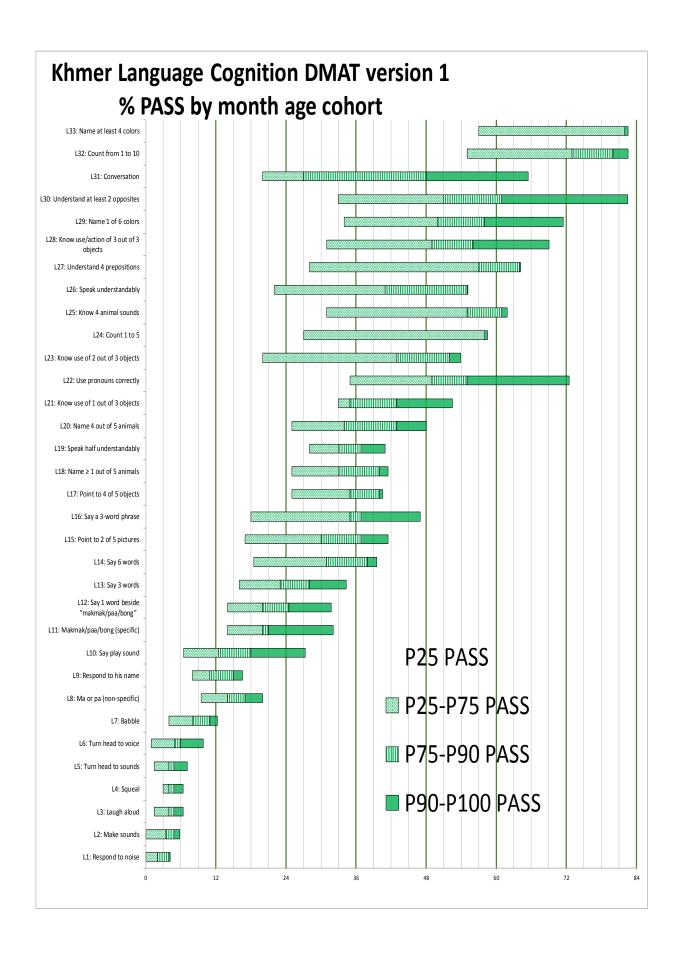


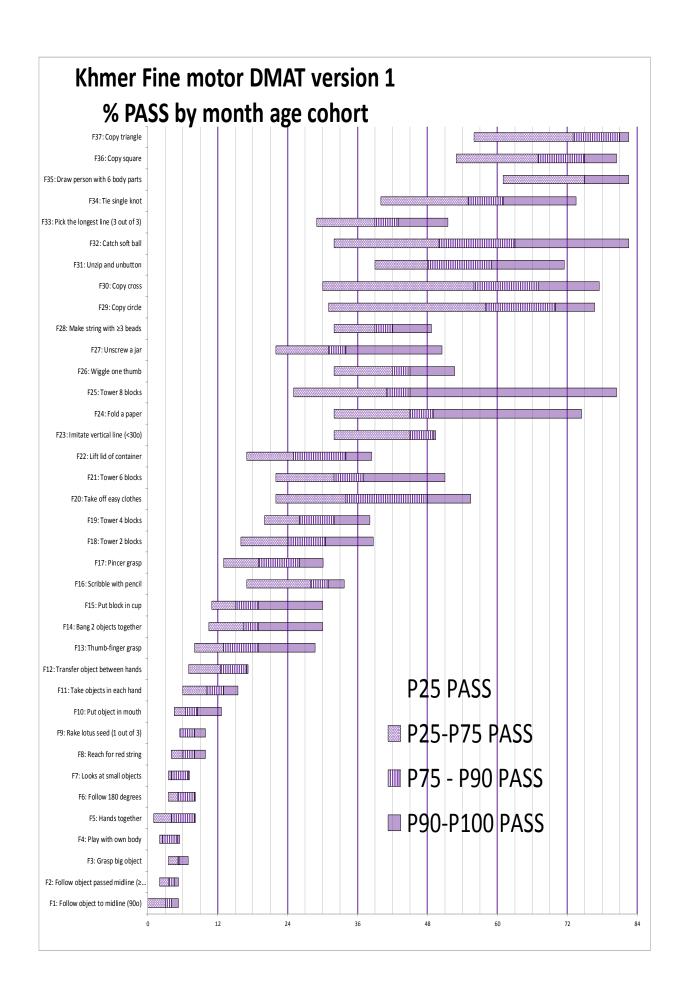


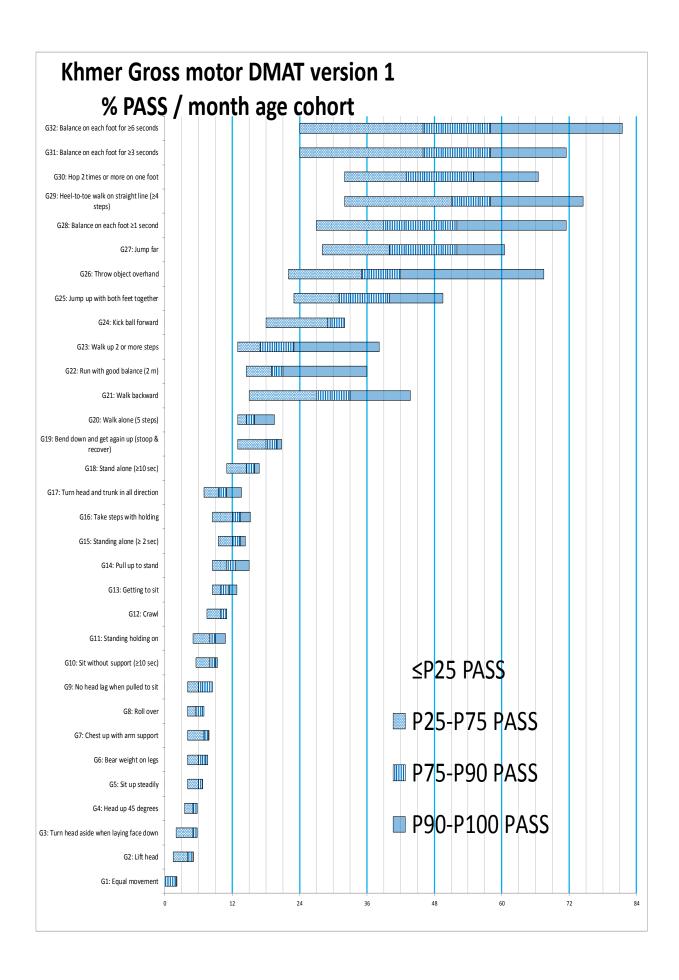


Khmer DMAT performance charts









Annex 10 – Cambodian Community-based DMAT (CB DMAT)

Health Cent	tre Develo	pmental N	Ailestone As	sessment	Tool (HC DN	1AT) (9	months – 5 y	rears) N	o
General Inf	formation	1	47.		9	(T)		*	
Child's name:		Gender:		Child's we	eight:	78776	of Birth:	Health	Facility:
Mother's nan	ne:	Father's na	ime:	Address o	f family:	Famil	y Tel:	Alterna	ntive tel.:
		Complet	e information a	above with p	parents and ex	plain wh	at you will do		
			on the child's agons. If needed,						
. 4 [. 100 100	38875358		<u> </u>				
1 year	Q C	• E	e age of 9-17 n Explore home a Can play with its Chuckle or laugh Roll over from s	nd other pla s own hands h aloud?	ces? and feet?		Yes	"NO" :	or more answers, b hospital cialist
1.5 years		• F	ne age of 18-23 Distinguish betv Pick up an objec Pick up and hold Walk 5 steps ald	ween strange at and put it d items in ea	e and familiar p in his mouth? ch hand?		Yes	☐ "NO"	e or more answers, o hospital ecialist
2 years		• F	ne age of 24-35 Drink from a cup Pick up an item Make any kind o Pick up an item	p without sp using the th of a single so	illing? umb and finger ound (e.g. 'da' o	r 'pa')?	Yes	☐ "NO"	e or more answers, o hospital ecialist
3 years		• C	e age of 36-47 Correctly point to Pick up a small in Bay at least 3 wo Run without fall	to at least 2 tem with its ords (except	body parts? thumb and ind for family men			☐ "NO"	e or more answers, to hospital ecialist
4 years		• F	e age of 48-59 Put on easy clot Wiggle each thu Gay at least a 3- ump up with bo	hes (e.g. shi imb from lef word phrase	rt, pants, skirt) t to right (like a e (e.g. want drin	dog's ta	il)?	☐ "NO"	e or more answers, to hospital ecialist
5 years	\$ 9	. F	e age of 60 mo Play well with or Button and unb Count 1 to 5 cor Throw an object	ther kids and utton its shir nsecutively a	d share its toys: rt, pant or skirt and correctly?	without l		☐ "NO"	e or more answers, to hospital ecialist
V -	200								
		Complete info	ormation below	w and inform	n family about	referral r	needs (if require	ed)	
	5.J								
No referral	Referr	al to:	Date of screen	ing:	Examiner nam	e:	Phone number	of examiner:	Signature:

Annex 11 – Newborn Triage Checklist



No Baby Left Out – **Newborn Triage Checklist gíz v**So



Name:			Date of	birth:		Outcome: alive / dead		
				eight:		Cause of death:		
Cellphone no.	.:	100	PMTCT:	1 0 / 2 0		Acting health facili	ty:	
Referral: yes	□ / no □		If referr	al, why:				
1) Evaluation	shortly after I	oirth (age > 1	.0 minutes) / TII	VIE:				
Birth weight	Apgar score	Maternal	Respiration	Skin & capillary	Movements	Others	Action to take	
	5 min	factors		refill time (CRT)				
< 1.8 kg □	<7 □		> 60 / min < 30 / min Grunting/ Nasal flare/ chest indrawings	Central Cyanosis Pallor CRT > 3 sec.	Movements only when stimulated No movements at all	Congenital Malformation Convulsion Foul smelling amniotic fluid	HIGH RISK Referral Immediate administration of IM antibiotics and referral to hospital with neonatal care	
1.8 −2.5 kg □	7-8 🗆	Maternal pyrexia > 38°C PROM > 18 h					AT RISIK Observation Dispensary: Referral to Health Center Health Center: Close Observation with observation chart. Kangaroo Mother Care for < 2.5 kg.	
> 2.5 kg 🗆	>8 🗆	None □	30 – 60 /min □ Normal breathing □	Normal colour □ CRT ≤ 3 s. □	Normal movements	None □	NO RISK	

Temperature	Respiration	Skin and CRT	Feeding	Movements	Umbilicus	Others	Action to take
> 38.0°C □	> 60 / min 🗆	Cyanosis	Not well or	Movements	Bleeding	Convulsion	HIGH RISK
			not	only when			Referral
< 35.5°C □	< 30 / min 🗆	Pallor	sucking	stimulated		Fontanelle	
						sunken or	Immediate administration
	Grunting/	Grey colour 🗆	Vomiting	No Movements		bulging 🗆	of IM antibiotics and
	Nasal flare/		after each	at all 🗆			referral to hospital with
	chest	Jaundice 🗆	feed 🗆			Irritable 🗆	neonatal care
	indrawings						
		CRT > 3 sec. □					
37.6°C − 38.0°C □							AT RISIK
							Observation
35.5°C − 36.4°C □							200 and 200 an
							Dispensary: Referral to
							Health Center
							Health Center: Close
							observation with
							observation chart
36,5°C − 37,5°C □	30 – 60 /min	Normal	Well 🗆	Normal	Not	None	NO RISK
		colour 🗆		movements	bleeding 🗆		Dispensary: Ready for
							discharge, counseling
	Normal	CRT < 3 sec. □					and R/V after 24h
	breathing						



No Baby Left Out – **Newborn Triage Checklist giz vso**





Weight	Temperature	Respiration	Skin and CRT	Feeding	Movements	Umbilicus	Others	Action to take
< 1.8 kg 🗆	> 38.0°C □	> 60 / min 🗆	Cyanosis	Not well or not	Movements only when	Bleeding	Convulsion	HIGH RISK Referral
	<35.5°C □	< 30 / min 🗆	Pallor	sucking 🗆	stimulated	Red or draining	Failure to pass meconium	Immediate
		Grunting/ Nasal flare/	Grey colour 🗆	Vomiting after each		pus 🗆	and/or urine □	administration of IM antibiotics and
		chest indrawings	Jaundice 🗆	feed □	No Movements		Fontanelle sunken or	referral to hospital with neonatal care
		0	CRT > 3 sec. □		at all 🗆		bulging 🗆	
					5		Irritable 🗆	
1.8 − 2.5 kg □	37.6°C − 38.0°C □		Pustula				Eyes swollen and/or pus draining	AT RISIK Observation
	35.5°C − 36.4°C □						a.a	Dispensary: Referral to Health Center
								Health Center: Close Observation with
								observation chart and antibiotic treatment for
								eye and skin infection. Kangaroo Mother Care for < 2.5 kg.
> 2.5 kg 🗆	36.5°C − 37.5°C □	30 – 60 /min 🗆	Normal color	Well 🗆	Normal movements	No bleeding	None 🗆	NO RISK Dispensary & Health Center: Ready for
		Normal breathing	CRT ≤3 sec. □			No Infection □		counseling and discharge

Time: initial	Time for this	Temperature	Respiration	Feeding	Movements	Weight (g)	Information:
observation	child	(°C)	Rate (/min)	1) Well	1) Normal	Measure only	If
(hours)				2) Not well	2) Not normal	every 24 hours	- Temperature:
0 hours							< 36°C or > 38°C or
(initial)							- Respiration Rate:
8 hours							< 30 /min or > 60 /min or
16 hours							> 00 / Hilli OI
24 hours							Feeding: 2 or Movements: 2 or
32 hours							weight loss > 300g in 48
40 hours							
48 hours							Referral to hospital with neonatal care unit
Add. Informati	on about the pat	ient:		•	•		

Annex 12 – Differences in performance (Cambodia, Malawi and Denver II)

MONTHLY AGE COHORT	Khmer month minus Malawi			Khmer month minus Denver			
Social domain (Khmer <u>faster</u> average, descending order)	P25	P75	P90	P25	P75	P90	Average difference
S36: Play kid games				-13	-20	-1	-11
S32: Three-step command	-9	-6	-13				-9
S34: Serve own food				-8	-9	-9	-9
S23: Point to 2 body parts	-7	-8	-5				-7
S24: Put on simple clothes with help	-8	-9	-7	-4	0	5	-4
S15: Greet with hand clasp	-6	-8	-9	3	6	4	-2
S33: Dress ((un)button / no help)				-7	1	3	-1
S6: Brief interest in toy				-2	-1	0	-1
S1: Look at face						0	0
S26: Comb hair with help				-1	1	0	0
S4: Smile responsively	1	1	1	1	2	2	1
S17: Hold & drink from cup	2	2	3	2	-1	0	1
S13: Play 'chab chaab'				-1	2	4	1
S3: Smile spontaneously		2	3		0	1	1
S5: Recognize its own hands				1	1	4	2
S19: Use spoon	2	3	4	1	3	3	3
S20: Imitate activities				2	5	6	4
S29: Tell own name & gender	0	3	10				4
S14: Indicate wants				3	5	6	4
S30: Name a friend				-1	6	9	5
S27: Wash and dry hand	5	7	1	4	13	7	6
S31: Put on T-shirt without help				5	8	15	9
S37: Help around the house	-18		-5	6	28	38	10

Fine Motor Milestones	Khmer- Malawi P25	Khmer- Malawi P75	Khmer- Malawi P90	Khmer- Denver P25	Khmer- Denver P75	Khmer- Denver P90	Average difference
F33: Pick the longest line (3	pass	pass	pass	pass -7	pass -9	pass -20	-12
out of 3)		7	10				
F27: Unscrew a jar	-5	-7	-10	42	-	44	-7
F30: Copy cross	-14	-4	1	-12	6	11	-2
F9: Rake lotus seed (1 out of 3)	-1	-2	-1				-1
F36: Copy square	-4	-6	-6	-3	1	12	-1
F28: Make string with ≥3 beads	2	0	-2				0
F7: Looks at small objects				1	-1	2	1
F26: Wiggle one thumb				-1	3	1	1
F8: Reach for red string				0	1	3	1
F3: Grasp big object				1	2	2	1
F5: Hands together	-1	1	4	-1	1	4	1
F2: Follow object passed midline (≥ 90o)				1	2	2	1
F10: Put object in mouth	2	2	4	-1	1	2	1
F19: Tower 4 blocks	2	-1	-6	4	4	8	2
F21: Tower 6 blocks	-2	-1	-2	3	7	6	2
F11: Take objects in each				0	3	4	2
hand						-	_
F1: Follow object to midline (900)		2	2		3	3	2
F6: Follow 180 degrees	3	3	5	1	1	3	3
F15: Put block in cup	1	2	4	2	3	6	3
F18: Tower 2 blocks	-1	-1	-2	3	7	10	3
F23: Imitate vertical line (<30o)	-1	-1	-3	5	11	10	4
F29: Copy circle	-9	1	6	-8	13	21	4
F25: Tower 8 blocks				1	8	4	4
F13: Thumb-finger grasp				1	4	9	4
F12: Transfer object between hands	2	6	10	2	6	9	6
F16: Scribble with pencil	-2	3	4	6	13	15	6
F14: Bang 2 objects together	6	8	8	4	7	8	7
F17: Pincer grasp	6	7	12				8
F35: Draw person with 6		,		11	13	10	11
body parts					1.4	24	1.0
F20: Take off easy clothes				9	14	24	16

Language Milestone	Khmer- Malawi P25 pass	Khmer- Malawi P75 pass	Khmer- Malawi P90 pass	Khmer- Denver P25 pass	Khmer- Denver P75 pass	Khmer- Denver P90 pass	Average difference
L24: Count 1 to 5	-30	-18	-26	-24	-4	6	-16
L30: ≥ 2 opposites	-21	-19	-19	-11	-9	-8	-15
L7: Babble	-2	-2	-1	-2	-1	-1	-1
L5: Turn head to sounds				-2	-1	-1	-1
L6: Turn head to voice	-1	2	2	-3	-1	-1	0
L27: Understand 4 prepositions	-2	-1	-9	-5	12	7	0
L3: Laugh aloud	-1	1	1	0	2	2	1
L4: Squeal				2	1	1	1
L28: Know use/action of 3 out of 3 objects	-2	-1	-1	-2	8	7	2
L1: Respond to noise		2	3		2	4	3
L2: Make sounds		2	3		4	4	3
L20: Name 4 out of 5 animals				1	2	7	3
L16: Say a 3-word phrase	-6	3	1	1	14	13	4
L9: Respond to his name	3	4	7				4
L26: Speak understandably	-2	9	19	-1	1	4	5
L19: Speak half understandably				11	7	1	6
L17: Point to 4 of 5 objects				1	9	9	6
L13: Say 3 words	5	5	7	5	7	10	6
L12: Say 1 word beside "makmak/paa/bong"				4	7	10	7
L15: Point to 2 of 5 pictures				-2	9	13	7
L8: Ma or pa (non-specific)	6	8	10	4	6	8	7
L11: Makmak/paa/bong (specific)				7	9	8	8
L14: Say 6 words	1	8	10	5	12	13	8
L18: Name ≥ 1 out of 5 animals				6	9	12	9
L29: Name 1 of 6 colors				5	11	13	10
L22: Use pronouns correctly				11	16	17	15
L33: Name at least 4 colors				21	32	27	27

Gross Motor Milestones	Khmer- Malawi P25 pass	Khmer- Malawi P75 pass	Khmer- Malawi P90 pass	Khmer- Denver P25 pass	Khmer- Denver P75 pass	Khmer- Denver P90 pass	Average difference
G29: Heel-to-toe walk on straight line (≥4 steps)	-18	-18	-22	-16	-10	-10	-16
G32: Balance on each foot ≥6 sec.	-15	-8	-3	-26	-19	-14	-14
G31: Balance on each foot ≥3 sec.				-13	0	2	-4
G30: Hop 2 times or more on one foot				-7	-4	4	-2
G11: Standing holding on	-2	-3	-3	-1	0	1	-1
G23: Walk up ≥2 steps				-1	-2	1	-1
G20: Walk alone (5 steps)	0	-2	-3	2	1	1	0
G25: Jump up with both feet together	-7	-11	-4	6	4	11	0
G5: Sit up steadily				2	-1	0	1
G15: Standing alone (≥ 2 sec)				0	1	2	1
G1: Equal movement			0			2	1
G22: Run with good balance (2 m)	1	2	2	1	1	2	1
G13: Getting to sit				1	1	2	1
G18: Stand alone (≥10 sec)				1	2	2	2
G12: Crawl	2	2	2				2
G10: Sit without support (≥10 sec)	1	2	2	1	2	2	2
G14: Pull up to stand	2	1	1	1	2	3	2
G8: Roll over	1	2	3	2	1	2	2
G6: Bear weight on legs	2	2	3	2	3	3	2
G9: No head lag when pulled to sit	2	3	5	1	2	2	2
G19: Bend down and get again up (stoop/recover)	1	2	2	2	5	6	3
G7: Chest up with arm support	2	4	4	1	3	3	3
G4: Head up 45 degrees				4	3	3	3
G27: Jump far	-2	-2	7	0	5	15	4
G2: Lift head					4	5	4
G24: Kick ball forward	2	7	3	2	8	9	5
G28: Balance on each foot ≥1 second				0	5	12	6
G26: Throw object overhand				5	11	7	8
G21: Walk backward				3	12	17	10

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