Mapping Children with Disabilities Out of School

Webinar 5 - Companion Technical Booklet

unicef

Mapping Children with Disabilities Out of School

Webinar Booklet

What this booklet can do for you

The purpose of this booklet and the accompanying webinar is to assist UNICEF staff and our partners to better understand the relationship between childhood disability and school attendance, and how to statistically identify and map out-of-school children.

In this booklet you will be introduced to:

- *The importance of tracking early childhood interventions.*

- *Tracking hard-to-find children who are not in school, for example those being hidden by their families or sent to live in institutions.*

- *Incorporating children in special schools into indicators for enrollment and attendance.*

- *Various supply- and demand-side barriers to receiving an education.*

- *Suggestions on what to do if data on children with disabilities is not readily available.*

- *Recommendations for incorporating data on disability into education indicators, when data on childhood disability is available.*

For more detailed guidance on programming for inclusive education, please review the following booklets included in this series:

1. Conceptualizing Inclusive Education and Contextualizing it within the UNICEF Mission
2. Definition and Classification of Disability
3. Legislation and Policies for Inclusive Education
4. Collecting Data on Child Disability
5. Mapping Children with Disabilities Out of School (*this booklet*)
6. EMIS and Children with Disabilities
7. Partnerships, Advocacy and Communication for Social Change
8. Financing of Inclusive Education
9. Inclusive Pre-School Programmes
10. Access to School and the Learning Environment I – Physical, Information and Communication
11. Access to School and the Learning Environment II – Universal Design for Learning
12. Teachers, Inclusive, Child-Centred Teaching and Pedagogy
13. Parents, Family and Community Participation in Inclusive Education
14. Planning, Monitoring and Evaluation

How to use this booklet

Throughout this document you will find boxes summarizing key points from each section, offering case studies and recommending additional readings. Keywords are highlighted in bold throughout the text and are included in a glossary at the end of the booklet.

If, at any time, you would like to go back to the beginning of this booklet, simply click on the sentence "Webinar 5 - Companion Technical Booklet" at the top of each page, and you will be directed to the Table of Contents.

To access the companion webinar, just scan the QR code.

Acronyms and Abbreviations

ADHD   Attention Deficit Hyperactivity Disorder

CMF   Conceptual and Methodological Framework (of UIS OOSCI)

CRC   Convention on the Rights of the Child

CRPD   Convention on the Rights of Persons with Disabilities

ECI   Early Childhood Interventions

EFA   Education for All

EMIS   Education Management Information System

ISO   International Organization for Standardization

LQAS   Lot Quality Assurance Sampling

MDG   Millennium Development Goals

MICS   Multiple Indicator Cluster Survey

OOSC   Out-of-School Children

OOSCI   Out-of-School Children Initiative

UIS   UNESCO Institute of Statistics

UN   United Nations

UNESCO   United Nations Education, Scientific and Cultural Organization

UNICEF   United Nations Children's Fund

WG   United Nation's Statistics Commission's Washington Group on Disability Statistics

I. Introduction

Key Points

- *Providing education to all children is an important, internationally recognized goal.*

- *To develop and evaluate policies to achieve universal education, data on out-of-school children is essential.*

- *Children with disabilities are over-represented among out-of-school children.*

- *Collecting data on out-of-school children with disabilities has special challenges that will be addressed in this booklet.*

Education is both the bedrock of a person's full participation in society, and also of a country's overall economic development. For this reason, Education for All (EFA), the Millennium Development Goals (MDG) and the Sustainable Development Goals all put a high priority on universal primary education. The Global Out-of-School Children Initiative (OOSCI) undertaken by UNICEF and the UNESCO Institute for Statistics (UIS) in 2010 aims to accelerate the achievement of these goals.

In order to successfully develop policies, implement them and evaluate their effectiveness it is important to have timely, reliable and high-quality data. While data from Education Management Information Systems (EMIS) keep track of children in school, they do not provide data on out-of-school children (OOSC). A recent publication by UNICEF and UIS provides a framework for collecting such data.[1] However, the UNICEF/UIS report highlights that a gap often exists when it comes to the collection of data related to children with disabilities.

The lack of data on out-of-school children with disabilities is troubling because children with disabilities are less likely to attend school, and when they do attend school they are less likely to stay in school and be promoted.[2] According to data from the World Health Study, which examined over 50 countries across different income categories, only 50.6 per cent of men with disabilities had completed primary education compared to 61.3 per cent of non-disabled men. For women, these figures were 41.7 per cent and 52.9 per cent, respectively.

However, comparisons of this sort understate the impact of disability on schooling, because they do not account for the age of onset. Most people with disabilities acquire those disabilities as adults, well after the ages when people typically attend school.[3] Studies in southern Africa show that children with disabilities are only half as likely as their peers without disabilities to have ever attended school. In Malawi, Namibia, Zambia and Zimbabwe only 9 per cent to 18 per cent of non-disabled children over five years old have never attended school, whereas the percentage of children with disabilities having never done so ranged from 24 per cent to 39 per cent.[4] Furthermore, this does not even account for the higher drop-out rates of children with disabilities. In India, the difference between school attendance for children with and without disabilities is even greater. In 2007, close to 40 per cent of children with disabilities were not enrolled in school. This rate was over four times as high as it was for children in Scheduled Tribes or Castes, who have non-enrollment rates of between 8 per cent and 10 per cent – and they are viewed as other excluded groups.[5] The overall enrollment rate of children in India is over 90 per cent. One study of 11 developing

countries found, as in India, that disability was a stronger predictor of educational enrollment than either gender or socio-economic class.[6]

Tracking the number of children with disabilities who are not in school can be challenging. EMISs only collect data on children in school, and they often do not collect data on disability status (see Booklet 6 in this series). Surveys that collect data on childhood disability in the general population often have methodological problems. Fortunately, this should be changing as UNICEF and the UN Statistical Commission's Washington Group on Disability Statistics (WG) have recently developed and tested a new survey module for improved childhood disability data collection that is in line with new theoretical developments on defining and conceptualizing disability (see Booklets 2 and 4 in this series).

Still, even armed with a new and improved survey for identifying children with disabilities there are many special issues involved in finding these children in order to map where they are located and uncover the barriers to schooling they face. This booklet provides an overview on accomplishing these tasks.

To learn more go to:

- UNICEF, State of the World's Children: Children with Disabilities, 2013 can be found at http://www.unicef.org/sowc2013/

- UNICEF/UIS, Framework for Monitoring Out-of-School Children and Adolescents in the ECA Region, 2014.

- UIS webpage on OOSCI, http://www.uis.unesco.org/Education/Pages/out-of-school-children.aspx

- WHO/World Bank, World Disability Report, 2011.

II. Special Issues in Collecting Information on Out-of-School Children with Disabilities

Key Points

- *Considering early childhood interventions (ECI) as part of schooling is important for children with disabilities because ECI has a big impact on future school attendance.*

- *Children with disabilities may be hard to find, either because they are hidden by their parents or because they are sent to live in institutions.*

- *Children who are attending special schools should be incorporated into education indicators.*

Collecting data on OOSC and on children with disabilities both pose challenges. Combining the two concepts creates even further difficulties. These pertain to early childhood interventions, hard-to-find children and children in special schools. Without an explicit focus on these populations, many children can easily be left out of UIS's Conceptual and Methodological Framework (CMF) for developing OOSC indicators.

Early Childhood Interventions

Research suggests that ECI can be particularly effective for children with disabilities, increasing the returns to schooling and thus promoting their enrollment and attendance. While studies of ECI do not generally have cost-benefit calculations, the results of these interventions can be dramatic, not just in terms of mental or physical functioning but also socialization.[7] Thus, the ability for children to remain in school – especially children with disabilities – is linked to receiving ECI.

The impact of early interventions for children with developmental disabilities has been extensively studied. For example, research looking at services to children under five finds that measures of cognitive capabilities increase between one-half and three-quarter standard deviations, which is highly significant.[8] In fact, when children with Down's Syndrome receive adequate services, the typical deterioration in cognitive capacity that occurs between the ages of 12 and 18 months can be prevented almost entirely.

If the goal is to reduce the number of children with disabilities who are not in school, efforts must start prior to school age. To monitor how well a country is moving towards the goal of full inclusion, data should thus also be collected on ECI. This includes interventions not only by the Ministry of Education but also by the Ministries of Health and Social Welfare. Even if the decision is made not to include quantitative indicators for ECI within UNESCO's Conceptual and Methodological Framework for reporting on OOSC, attention should be paid to this matter when developing a strategy for full inclusion. Any report on OOSC with disabilities should at least include a review of available research on ECI. For more detailed information regarding early childhood intervention, please see Booklet 9 in this series.

Hard-to-Find Children

Children with disabilities are often difficult to locate with standard data-gathering tools for two important reasons: attitudes towards disability and institutionalization (for more information on data collection see Booklet 4 in this series).

Attitudes towards disability of the public in general, as well as from data collectors and respondents, can have a significant impact on the ability to collect good-quality data on children with disabilities. This can be the result of different viewpoints about what constitutes a disability, as well as the stigma or shame the condition can arouse. Knowledge, belief and attitudes about disability vary not only across countries but often within countries, as well.

In many countries, people believe that disability results from incest, a sin of the parents, or from divine displeasure.[9] In countries with a tradition of reincarnation, disability is sometimes believed to be the result of punishment for sins in a past life. This can make interviewers reticent about even asking about disability. In fact, in some societies people believe that even talking about a child with a disability will cause the parents to have future disabled children.[10] For these reasons, interviewers have been known to not ask disability-related questions altogether because of their discomfort, and so only record people they can easily perceive as having a disability – thus missing many people with 'invisible' disabilities, such as those with learning disabilities. Parents might also want to hide children with disabilities – or the fact that their children have disabilities – because it could impinge on the marriage prospects of their non-disabled children, their fear being that people would not want to marry into a family with disabled members.

These attitudes are part of the reason why when disability data is collected, the word 'disability' is never used. Instead, data collection refers to identifying children who have difficulty doing certain activities. While not eliminating this problem, such an approach reduces it.

Data-gathering methodologies must be sensitive to the fact that parents may not admit to their children's presence in their homes and interviewers may be reluctant to broach the subject. Reliance on community workers who may know about family members with disabilities is one strategy. When birth registries or registries of people receiving disability benefits exist, they too can alert enumerators about the presence of family members, although parents of children with disabilities might be less likely to register their births in the first place.

Another important issue is institutionalization. Many times children with disabilities are sent to live in institutions.[11] This may result from stigma or shame, but can also result from parents feeling they do not have the capacity to care for their children, or simply because of social norms that suggest children with disabilities 'belong' in such places. Moreover, some children with disabilities may be living in juvenile detention centres, because of committing crimes or undertaking other antisocial behavior. In the United States, for example, estimates are that nearly 70 per cent of children in juvenile detention have disabilities, primarily Attention Deficit Hyperactivity Disorder (ADHD) and cognitive disabilities.[12]

Standard sampling designs for household surveys do not include the institutionalized population, and thus many children with disabilities could be missed with ordinary data-gathering tools. If the sample design cannot incorporate such institutions, then any study of OOSC should at least include attention to administrative data on children living in residential institutions.

EMIS reports should definitely incorporate any information about children living in institutions and the extent to which they are receiving any educational services – and the quality of those services.

Special Schools

Children with disabilities attend both 'regular' schools and 'special' schools. Even within regular schools they may be segregated into self-contained special classrooms. The special schools they attend could be run by the government or by private entities. Even when they are run by the government, they may not be run by the Ministry of Education but instead by the Ministry of Social Welfare, which typically lies outside the EMIS. Thus, it is important that data on children in special schools is collected in a manner consistent with the EMIS so the data can be merged.

Children with disabilities attending school should be disaggregated by the type of setting in which they are being educated. What percentage is attending regular schools as opposed to special schools? Within regular schools what percentage is attending regular classes?

Moreover, it should be noted that some special schools may not have grades per se, but operate on more of an open-classroom/mixed-grade model. This means that not only may it be impossible to have grade-by-grade breakdowns, but it may not be possible to generate indicators for repeating grades or promotions for children with disabilities attending special schools. Reporting on children in special schools may thus have to focus on age, more than grade.

Activity

- List all the places a child with a disability could be during the day other than in a regular classroom in a regular school.

- Where can you get information on these children presently? Which surveys? Which administrative records?

- If data is not available, what agency is responsible for knowing about these children? What would be the appropriate source of information about them?

III. Barriers to School Participation

Key Points

- *Data on OOSC with disabilities should be linked to information on barriers to schooling in order to develop effective strategies for getting children with disabilities into school.*

- *Demand-side barriers include both socio-cultural and economic barriers.*

- *Supply-side barriers include inaccessible materials and facilities, lack of teacher capacity and flexible curricula, and lack of assistive devices.*

- *Policy barriers include lack of a strategy on inclusion and lack of administrative capacity.*

Collecting data on OOS children is a first step in identifying the nature and scope of the problem, and being able to monitor the success or failure of various interventions to get children into school. But simply knowing about the existence of the children is not enough. What is needed is to identify the nature and extent of those barriers that are keeping children from attending school. By examining the correlation of the existence of those barriers with the number of out-of-school children, we can begin to identify the key bottlenecks that are preventing children from attending school, and fashion our policies to prevent them.

This section contains a brief description of the types of barriers that keep children with disabilities out of school. Indicators for these barriers should also be developed and data collected accordingly, to be analyzed in conjunction with data on out-of-school children.

Demand-Side Barriers

These are the factors that contribute to parents' and children's decision to not attend school. Assessing these barriers provides insight into the social and economic levers that could be used to reduce the number of out-of-school children.

Socio-Cultural. This dimension focuses on social and cultural forces that undermine the chances that a child with a disability will attend school.

The attitudes of teachers and school administrators are critical. Many children may be dissuaded from going to school, or decide to drop out because of the treatment they receive from school staff. Inclusive education policies will only be implemented to the extent that people doing the implementation believe in them.

Parental attitudes are also important, and can lead to a child not attending school They can take the form of pity, or the belief that children with disabilities are unable to take care of themselves. Some parents remove their children from school in order to protect them. Sometimes this is even seen as kindness; sometimes it is because they feel a great deal of shame at having a child with a disability and wish to keep that child hidden; and sometimes – even if they feel no shame – parents can be afraid to let their children experience a harsh, unaccommodating world, especially if they have little hope of their children being successful in it. Parents of children without a disability sometimes fear 'contamination' from children with a disability, or

worry that they will soak up a disproportionate share of limited resources away from their own children. This can also lead to pressure on the school system or the parents of children with disabilities to not send children to school. Finally, negative attitudes and doubts about capacity can become internalized among children and youth with disabilities and undermine their motivation to participate, which can lead to dropping out.

The strength and nature of these attitudinal barriers can differ significantly across countries, and even within a country.

Economic. Parents may decide that educating their child with a disability is not in the family's economic interest, given the extra costs they face and the expected returns from education.

In addition to typical costs that all parents face – such as uniforms and school books – children with disabilities face additional costs. The primary cost is transportation, which is often cited as a major barrier to enrollment.[13] It can be a bigger barrier for children attending special schools because those schools are often not in the community and so come with more extensive transportation needs. Transportation costs are not only monetary, but can also involve the time of other family members who are required to offer assistance.

Another economic factor is the expected economic return to an education. As stated above when referring to attitudes, the expected returns might be low because of an underestimation of what people with disabilities can achieve. But they might also be rooted in the reality of barriers to employment. To the extent that barriers to employment exist – for example, inaccessible transportation and workplaces as well as discrimination against people with disabilities – the economic returns to education will be lower. That means when families are evaluating the costs and benefits of an education, they may be more inclined to not send their child with a disability to school, especially if they have other children without disabilities and cannot afford to send them all. This means that programmes designed to help youth with disabilities transition from school to work might provide an added incentive to send children with disabilities to school – if those programmes prove to be successful.

Evidence does suggest, though, that schooling is economically beneficial to children with disabilities. For example, one study in Nepal showed that children with disabilities actually experienced a significantly higher rate of return from education than their non-disabled peers.[14] This is because combining having a disability with a lack of education is particularly limiting for future economic activity.

For more information on demand-side barriers, please see Booklets 1, 3, 7 and 13 in this series.

Supply-Side Barriers

Inaccessible Facilities. The most obvious form of inaccessibility is for physical spaces: if children cannot physically access schools, then they cannot attend.

Children who use wheelchairs need ramps instead of stairs. They also need doorways that are wide enough to accommodate them and that can be opened easily or automatically, as well as lifts to attend classes on upper floors. Children with non-physical disabilities may also face physical accessibility problems. For example, blind children may have particular problems with poorly maintained sidewalks or unregulated traffic crossings. In schools, a major barrier to attendance is inaccessible toilets. For more information, please see Booklet 10 in this series.

Inaccessible Materials. The use of inaccessible materials is another barrier to attending school. Once again, if children cannot participate fully in the classroom then they will be less motivated to attend.

Children who are blind need either Braille books or audio books. Children with vision problems may also not be able to read signs or may not be able to use computers without special software. Children who are unable to hear require sign language interpretation. Children with cognitive difficulties might need simplified forms of information – either easy-to-read books or easy-to-read signage. For more information, please see Booklet 10 in this series.

Lack of Teacher Capacity. Teacher training on inclusive education is at the very core of full inclusion, but very few teachers in developing countries have much exposure to inclusive education through pre- or in-service training.[15] Lack of teacher capacity can lead to non-attendance if the child does not have a positive experience at school.

Such training is not only important for learning instructional techniques and class management, but also to help change attitudes towards children with disabilities.[16] Capacity building goes beyond one-off training, but includes providing ALL teachers with a minimum level of adequate training that can support the learning process of all students and develop a spirit of collaboration that allows specialists to offer ongoing support – either within the school or through regional resource centres.

Also included in this category is children's access to various specialists who can provide needed services such as speech therapy, physical therapy and occupational therapy, as well as teaching assistants. For more information, please see Booklet 12 in this series.

Lack of Flexible Curricula. A hallmark of inclusive education is the notion of a child-centred and flexible curriculum.[17] This again promotes the attendance of children with disabilities and can lead to fewer out-of-school children with disabilities, by making the school more adaptive to their challenges and strengths.

A flexible curriculum allows teachers to adjust the content and means of presentation to the strengths and challenges of particular children. This is not a separate method for children with disabilities, but rather a different approach to education: material does not have to be presented in a uniform manner; while there are a set of core concepts all children are expected to address, expectations on the extent and speed of their learning are adjusted based on the child's capabilities and learning style; and teachers are allowed to modify and make substitutions in learning content, and – in extreme cases – omissions in content, but without changing the learning purpose.

In many countries, however, the approach is rote learning of an inflexible curriculum that cannot be adapted to individual children's learning needs, challenges and strengths. No modifications are made in terms of

what material is presented, how that material is presented, or how children's success is measured. This 'one-size-fits-all' approach can create barriers to children who require accommodations to succeed. For more information, please see Booklet 11 in this series.

Lack of Assistive Devices. The lack of assistive devices can also pose a significant barrier to attending school. The extent of that barrier depends on other factors – such as the willingness of family members and teachers to provide assistance, and the overall accessibility of the environment. But clearly easier access to such devices would be a factor in getting some children with disabilities into school.

These devices 'run the gamut' from very simple to more complex. They include a wide range of devices such as modified furniture, devices for helping with gripping and manipulating small objects for children with fine motor difficulties, canes, walkers, wheelchairs, prosthetics, Braille and audio books, computer screen readers, low-vision magnifiers, hearing aids and others. For more information, please see Booklet 10 in this series.

Political, Governance, Capacity and Financial Bottlenecks

Article 28 of the Convention on the Rights of the Child (CRC) recognizes the right of all children to receive an education, stating that primary education should be compulsory and free to all, and that secondary education should also be made available and accessible to every child. Similarly, Article 24 of the CRPD calls for children with disabilities to have access to 'an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live. This includes the provision of reasonable accommodations to children's needs along with adequate support to maximize economic and social development.' The establishment of these principles in a nation's laws is a fundamental step to ensuring those rights. The lack of such a law poses not only a legal barrier to enforce those rights but sends a signal to society that such rights are not important.

Lack of Strategy on Inclusive Education. A law ensuring the right of children with disabilities to go to school is only a first step.

Many countries have such laws, but they are not well implemented or enforced. One bottleneck to their effective enforcement is the lack of an agreed-upon and formally adopted strategy for moving towards an inclusive education system. To be effective, this strategy should have:

• Quantifiable goals.
• Action plans that lay out concrete actions, timetables and responsible parties.
• Structures to oversee and inform such implementation, such as coordinating committees or councils.
• The involvement of Disabled People Organizations or other mechanisms for civil society engagement.
• Adequate budgets to implement the action plans.

Lack of Administrative Capacity. Moving towards inclusion involves coordinating many different activities and applying new approaches.

This requires administrative capacity. In addition to teacher training, it is important that administrators at the school, district and national level also be trained in inclusive education, as well as being given the resources, personnel and discretion to implement these changes in a coherent fashion suitable to the context they are operating in. This requires clear lines of communication between school administrators and the coordinating committees or councils overseeing an inclusive education strategy.

Activity

- What do you think are the main demand-side barriers to participating in school? Do they differ by gender, ethnicity, region of the country, or other factors?

- What do you think are the main supply-side barriers to participating in school? Do they differ by gender, ethnicity, region of the country, or other factors?

- Are there any recent policy reforms that have addressed them? What data could you use to determine if they are working?

- What would be the easiest factors to address, and how would you address them?

Notes

IV. Reporting on Childhood Disability

Key Points

- *OOS Children reports need to focus both on the child's difficulties and also the barriers they face in the environment that are preventing their participation in school.*

- *Data can be derived from a variety of sources – surveys and administrative.*

- *When data on children with disabilities is available its quality should be assessed and all education indicators should be disaggregated by disability.*

- *When data on children with disabilities is not available, then qualitative work can be done in the short term as quantitative data systems are developed.*

- *Disability indicators can be incorporated into UNESCO's Conceptual Methodological Framework, used for reporting on OOSC.*

Disability arises from the interaction between children's impairments and the environment they live in. It is the interaction between their functional capacity and the barriers they face that lead to their lack of participation in school. Therefore, it is important when gathering information on OOS children with disabilities that both data on the child's functional difficulties and the barriers they face be collected. Section II of this booklet highlighted the key issues in collecting data on children with disabilities who are not in schools. Section III highlighted the barriers that may be preventing those children from attending school. In this section, we will guide you through developing ways in which to report on both. That is, where does one turn to in order to get the data for reporting, and what steps can be taken if that data is not currently available or of good quality? In other words, the previous sections highlight the issues to consider, while this section discusses potential sources of data and outlines some approaches when data is not currently available.

Sources of Information

To learn more go to:

- *Booth, Tony and M Ainscow, 'Index for Inclusion: Developing and learning and participation in schools,' Centre for Studies on Inclusive Education, 2002. Can be found at*
  http://csie.org.uk/resources/translations/IndexEnglish.pdf

- *McLeskey, J., N. Waldron, F. Spooner, B. Algozzine, (eds.) Handbook on Effective Inclusive Schools: Research and Practice, Routledge Press, 2014.*

- *UNICEF, State of the World's Children: Children with Disabilities, 2013. Can be found at*
  http://www.unicef.org/sowc2013/

Information on disability can be found in a variety of sources. As explained later in this section, however, care must be taken in assessing the quality of these data. Possible sources include:

Censuses. National population censuses often contain questions on disability that can be useful for making general prevalence estimates and noting regional differences in prevalence. Unfortunately, these questions are often of poor caliber, and even when they are not are almost never suitable for children. They will tend to significantly underestimate the prevalence of children with disabilities – especially those with less severe impairments.

Household Surveys. The Multiple Indicator Cluster Survey (MICS), which is UNICEF's tool for assessing the well-being of children, has optional questions on disability that have been included in a number of countries. Recently, these questions have been improved and tested in a number of countries. Other potential sources of survey data are Household Income and Expenditure Surveys, Living Standard Measurement Surveys, and Demographic and Health Surveys. Unfortunately, few of these have data on childhood disability – although they are worth investigating.

National Disability Surveys. A number of countries have conducted special national surveys on disability. These are potentially a rich source of data. Recent examples of government-sponsored surveys include national disability studies in Tanzania, South Africa and Indonesia. WHO is currently developing a Model Disability Survey.

Administrative Data. Some administrative data systems collect information on disability. A recent review of EMIS forms by UNICEF found that about half of all EMISs collected some type of information, although that information was generally of poor quality. As stated above, UNICEF now has a guide with recommendations on questions about children and the environment that are more suitable for analyzing the impact of disability on children's schooling. Countries that have disability benefits or other programmes targeting children with disabilities will have administrative data for those programmes, as well.

Literature reviews. There is a broad literature based on both qualitative and quantitative data that has been published focusing on a wide range of countries. Data is often not official government data and the samples used are not always nationally representative, but these studies can still provide important insights into the nature and extent of various barriers faced by children with disabilities.

Disabled People Organizations. Most countries have disabled people organizations that are working for the rights of people with disabilities and/or providing services. These organizations will generally have publications and other materials outlining the major issues that they see within the country. Contacting these organizations can provide important information about the attitudes of people with disabilities and their insights into key barriers, as they have first-hand knowledge of living with a disability in a particular country context.

What to do if there is Data on Children with Disabilities

Assess the Quality of Data. Any interpretation of indicators pertaining to children with disabilities should be made in light of the quality of those data. In assessing the quality of data on disability, the first issue is how are children with disabilities identified? As explained in Booklet 4 in this series and in the UNICEF/WG *Survey Module on Child Functioning and Disability: Implementation Manual:*

- The best method for identifying children with a disability is with functional questions (for example, 'compared to other children of the same age, does your child have difficulty walking?') that allow for scaled responses, for example: 'no difficulty', 'some difficulty', 'a lot of difficulty', 'cannot do'.

- Questions need to be designed explicitly for children of particular age ranges.

The UNICEF/WG survey module on child functioning and disability takes this approach.

Moreover, in assessing quality of data it is also important to assess information that pertains to the environment. UNICEF and the WG are also developing questions in this area as it pertains to education. Do the data address structural and attitudinal barriers that prevent children with impairments from attending school?

Disaggregate Data by Disability Status. If data on childhood disability exists then all indicators used for assessing the well-being of children should be disaggregated by disability status. However, disability is a very diverse phenomenon. Children can have many types of disabilities – physical, sensory, cognitive, psycho-social and communication – and the barriers that they face might be quite different. Therefore, if possible it is preferred that data be also disaggregated by type of disability. Moreover, disability varies by degree. Some children have relatively low support needs whereas others have very high support needs. In some circumstances, people with very low support needs might face smaller barriers – for example, children with vision problems correctable by glasses discussed earlier in this paper. But this is not always the case. If children with this minor impairment and small support needs are not capable of getting pairs of glasses, the impact on their lives could still be quite substantial. Examining the impact of disability by type and degree could thus lead the researcher to identify particular areas where barriers and bottlenecks are impacting children with various types and degrees of impairments.

Other social factors could interact with disability, as well, and so should be included in the disaggregation. The two most obvious are gender and region of residence. Attitudes and expectations of girls are often different to those of boys, and some research shows that disability can have particularly negative impacts on them.[18] Also, the level of infrastructure and the capacity of the educational system in rural and urban areas can also differ dramatically, so that children with certain impairments might face higher barriers depending on where they live.

What to do if there is No Data on Children with Disabilities

There is a reasonable chance that in some countries data on children with disabilities might be non-existent, or be of such poor quality (for example, based on questions such as: 'Does your child have a disability?') as to be not particularly useful. Nevertheless, there are several approaches that could be used in the short term to help collect information that could be useful in designing a strategy aimed at increasing school enrollment and attendance for children with disabilities.

The first approach is to undertake qualitative work that explores the major barriers to school participation. This can consist of focus groups of various stakeholders and also structured interviews with key school and government officials. In designing focus groups, it is important to keep in mind the significant diversity of the population of children with disabilities. Children with disabilities should include those with all types and degrees of disabilities. Because the nature of the barriers they face can be different, it is probably appropriate to have different focus groups by type of disability. Care should be taken to make sure children and their parents can participate fully. For example, sign language interpretation should be available, and interviewers should undergo training on how to interact with people with disabilities, especially those with cognitive disabilities who might require extra patience and a simpler approach to questioning.

The second approach is to undertake school accessibility audits. These are particularly useful to assess the physical accessibility of schools, but also whether their modes of communication are also accessible. Audits

can be done on a random group of schools in different geographical areas to get a sense of the main barriers children face. These audits should be carried out using international standards.

> The International Organization for Standardization (ISO) provides accessibility standards that can be adapted to take into account the local context. In regards to the built environment, ISO 21542:2011, Building Construction – Accessibility and Usability of the Built Environment delineates a set of requirements and recommendations concerning construction, assemblies, components and fittings. Audits should be carried out in conjunction with Disabled People Organizations, which are particularly familiar with accessibility barriers in the local context. An example of an audit tool used for schools in the United Kingdom can be found at the following url: https://schools-secure.essex.gov.uk/pupils/sen/the%20equality%20act%20and%20accessible%20schools/pages/accessauditchecklist.aspx

The third approach is to undertake a survey using Lot Quality Assurance Sampling (LQAS) to uncover the range of disability prevalence and most important barriers.[19] This is a sampling method deigned to provide accurate prevalence rates with relatively smaller samples, compared with typical household surveys, and thus at much lower cost. WHO has recommended this technique for computing indicators such as vaccination rates. It can be used to get at disability prevalence, but only if high-quality questions are asked (like the new MICS module). While this can generate national estimates, it will not generate regional ones. Finally, efforts should be made to identify appropriate data tools (surveys and administrative) that could potentially fill data gaps, and develop plans on how to modify them to capture important data. This issue will be revisited in the final section of this booklet.

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V. Constructing Disability Indicators

Key Points

- *Considering early childhood interventions as part of schooling is important for children with disabilities because ECI has a big impact on future school attendance.*

- *Frameworks exist for developing indicators on the inclusivity of the school system, which will also impact whether children attend and stay in school.*

- *Indicators are also needed to track students who may be in special schools or institutions.*

- *To create a full picture of OOSC and children at-risk of being out of school it is important to leverage all existing data systems.*

This section proposes how to integrate disability into the Conceptual Methodological Framework of UNICEF's and UNESCO's Global Initiative on OOSC. It first discusses issues pertaining to disaggregating general indicators by disability, and then indicators addressing particular needs in the area of children with disabilities.

General Indicators on Children with Disabilities

The CMF provides a framework and methodology for undertaking a national study on the extent and nature of children's exclusion from formal education. This section of the booklet serves as a companion to the CMF, highlighting how the issues and concerns of children with disabilities can be incorporated into its system of indicators. It addresses particular considerations in integrating children with disabilities into the CMF typology for measuring exclusion.

Importantly, this framework looks not only at current educational activity, but also at the age appropriateness of that activity and whether the child is experiencing factors that lead to exiting the educational system. These factors can be linked directly to the education experience itself, or to external factors that are on-going in the family or community.

Within each of the CMF dimensions there are important considerations for addressing the needs and situations of children with disabilities. In terms of Dimension 1, while pre-primary education and school readiness is an important issue for all children, it is of particular importance to children with disabilities.

> The CMF outlines a five-dimensional model for examining children's exclusion from education. Those dimensions are as follows:
>
> **Dimension 1**: Children of pre-primary-school age who are not in pre-primary or primary school.
> **Dimension 2**: Children of primary-school age who are not in primary or secondary school.
> **Dimension 3**: Children of lower-secondary-school age who are not in primary or secondary school.
> **Dimension 4**: Children who are in primary school but at risk of dropping out.
> **Dimension 5**: Children who are in lower-secondary school but at risk of dropping out.

A key question is how to record the participation in early intervention programmes designed for pre-school-aged children with disabilities. The CMF framework pertains to formal education, which is defined as 'the system of schools, colleges and universities and other formal educational institutions that normally constitutes a continuous ladder of full-time education'. Early intervention programmes for children with disabilities usually exist outside that 'ladder' and may not even be run by the Ministry of Education, but by the Ministry of Health. Leaving them out of an OOSC report, however, misses a potentially vital avenue for monitoring the impact of services on the successful participation of children with disabilities within the formal education system.

The issue of formal vs. informal education also arises for Dimensions 2 and 3, which capture enrollment and attendance of school-aged children at the appropriate level of education. In some countries, children with disabilities are sent to special schools, which may or may not be considered part of the formal education system. In India, for example, the education of children with disabilities is considered under the purview of the Ministry of Social Justice and Empowerment.[20] Some children are provided education in their homes if they are deemed incapable of attending school.

While in one sense classifying these children as being outside of formal education is important, it is not the same thing as their having no connection to education services – even those provided by the government. Furthermore, the strategies to include them in formal education could be different to the strategies for reaching children who are totally removed from any government programmes. Therefore, when it comes to disaggregating data by disability in Dimensions 1, 2 and 3 – as discussed later – indicators in addition to those specified in the CMF framework may be required.

Dimensions 4 and 5 relate to drop-out risk where disaggregation by disability is especially important since the lack of accessible schools, inclusive curricula and teachers trained in inclusive education could all pose significant barriers to staying in school. Disability is definitely a risk factor for dropping out.

The CMF has extensive information on indicators pertaining to enrollment, attendance rates and dropouts, as well as indicators on gender parity and under- or over-age school participation. It is important to have these indicators disaggregated by disability. In addition, because of the significant differences in the types of barriers that children with different types of disability face, it is advisable to further disaggregate these by type of disability: physical, intellectual, vision, hearing or behavioural/psycho-social.

Dimension 1
The first indicator in the CMF is the percentage of children of pre-primary age in pre-primary or primary education, by sex or other characteristics. This is simply the number of children of pre-primary-school age enrolled in pre-primary or primary education divided by the total number of children of pre-primary-

school age. In addition to generating this indicator for children with disabilities, it is important to include an additional indicator:

The number of children with disabilities of pre-primary-school age participating in ECI programmes, including those specifically for children with disabilities, divided by the number of children with disabilities of pre-primary-school age.

This can be further broken down into rates for children with disabilities also in regular pre-primary education programmes, and those who are not. As early intervention is of particular importance for helping the learning capabilities of children with mental disabilities, this indicator should also be disaggregated by type of disability.

Dimensions 2 and 3

The CMF indicators for these dimensions (as explained in detail in the CMF Framework) are the net enrollment rate, adjusted net enrollment rate (taking into account that some children are attending age-inappropriate grades), and the net and adjusted net attendance rates. The CMF then goes on to define the gender parity index, which is simply the ratio of the adjusted net enrollment rate for girls as compared to boys. A similar disability parity index should also be calculated. This would be the ratio of the enrollment rate for children with disabilities to the enrollment rate of children without disabilities. A value of one would thus mean that children with disabilities do not face barriers to school enrollment greater than their non-disabled peers. Again, to isolate the importance of particular barriers facing children with different issues, it would be advisable to generate this indicator for different types of disability.

Dimensions 4 and 5

These dimensions focus on children who are at risk of exclusion, of whom children with disabilities are expected to be a significant component. The CMF defines the survival rate of children in school as the number of children entering the first year of primary (or secondary) education and reached the last grade of primary (or secondary) education divided by the number of children who entered the first year of the corresponding level of education. Thus, survival rates are simply 100 minus the dropout rate. The CMF also includes a set of indicators to gauge the extent of underage or overage enrollment or attendance, and grade repetition. All of these should be disaggregated by disability and, where data allows, by the type of disability, as well.

School-Level Indicators

Indicators at the school level are also needed because the school environment factors into whether children with disabilities attend school or are at risk of dropping out. These indicators are more difficult to standardize because they are reliant on the school environment. Booklet 6 in this series puts forth a recommended set of indicators appropriate for school in different environments pertaining to the accessibility of school entrances and toilets and training of teachers on children with disabilities that can be collected through an Education Management Information System. Other data on the inclusivity of schools can be obtained through surveys or audits.

Indicators for schools – and for the education system in general – generally address three areas: attitudes, policy and practice. One such system developed for UNESCO puts forth a detailed set of indicators for inclusion specifically designed to support the development of inclusive schools.[21] Basically, it describes in detail the attributes of an inclusive school, and can be described as an initiative for developing inclusive schools in diverse contexts.[22]

While an important checklist for an evaluation of a particular school, many of the items in the UNESCO indicator list are difficult to measure, especially in a quantifiable, systematic way comparable across schools and school districts, let alone internationally. One approach, though, could be to simply ask stakeholders which indicators they believe are met and use the percentage of respondents answering in the affirmative as a target. They are also too numerous to serve as system indicators. One strategy could be to construct a composite indicator for each category (for example, Creating Inclusive Cultures) based on the number of indicators receiving over a certain percentage of positive responses. The items and cutoffs used would probably have to be adjusted to the country context.

Another approach for inclusive-education indicators can be found in the Box below. This system, devised by UNICEF, is more at a system level and it is specific to the issue of disability. It is a rubric for assessing national policy and an overview of the school system as a whole. It is designed as a qualitative assessment made by in-country education specialists on how they perceive the education system to be operating as a whole. Countries are 'graded' on a scale of one to four in six categories: Law/Policy, Physical Environment, Materials and Communication, Human Resources, Attitudes and the EMIS. UNICEF combines these ratings into a single index.

High (Score 4)	Medium (Score 3)	Questionable (Score 2)	Weak (Score 1)
Law/policy. There is a law/policy establishing the right of all children to receive an education, with an explicit mention of children with disabilities. And also a national plan on inclusive education.	*Law/policy.* There is a law/policy establishing the right of all children to receive an education, with an explicit mention of children with disabilities.	*Law/policy.* There is a law/policy establishing the right of all children to attend school, which implicitly but not explicitly includes children with disabilities.	*Law/policy.* No law/policy establishing the right to education for children with disabilities.
Physical Environment. All schools have accessible classrooms and/or reasonable accommodations that remove all physical barriers (including accessible toilets and recreation areas).	*Physical Environment.* More than half of schools have accessible classrooms and toilets, at times because of an accessible design and at times because of makeshift adjustments.	*Physical Environment.* Less than half of the schools are accessible (including toilets). Some schools may have accessible classrooms, or use makeshift ramps.	*Physical Environment.* In general, schools are not accessible. Children with physical disabilities have great difficulty or are completely unable to access school facilities (including toilets).
Materials and Communication. Assistive devices and materials are available in most regular schools. Books and other materials include positive references to children with disabilities.	*Materials and Communication.* Assistive devices and materials are available in special schools but in less than half of regular schools. A few books and other materials include positive references to children with disabilities.	*Materials and Communication.* Assistive devices and materials are available in special schools, but not in regular schools. Little or no mention of disabled children appears in books or materials.	*Materials and Communication.* Assistive devices and materials are generally not available in schools. Books and other materials make no mention of children with disabilities.
Human Resources. Most teachers and school administrators receive training on inclusive education. All schools have access to specialists on inclusive education for consultation. Most children have access to speech, physical and occupational therapists, as needed.	*Human Resources.* More than half of teachers and school administrators receive training on inclusive education. More than half of schools have access to specialists on inclusive education for consultation. Some access to speech and physical therapists exists.	*Human Resources.* Less than half of teachers and school administrators receive training on inclusive education. Less than half of schools have access to specialists on inclusive education for consultation. No access to speech and physical therapists exists.	*Human Resources.* Teachers and school administrators receive no training on inclusive education. Teachers have no specialists to consult with on issues pertaining to educating children with disabilities. No access to speech and physical therapists exists.
Attitudes. Teachers and school administrators support including children with disabilities in regular schools, and are willing to make significant adjustments to ease their inclusion. Curricula and classroom management allow for the flexibility of addressing individual students' needs.	*Attitudes.* Teachers and school administrators do not object to including children with disabilities in regular schools, and are willing to make small adjustments to ease their inclusion.	*Attitudes.* Teachers and school administrators do not see the value of including children with disabilities in regular schools but do not make explicit objections. They do not feel it is their responsibility to make any adjustments to ease their inclusion.	*Attitudes.* Teachers and school administrators object to the inclusion of children with disabilities in regular schools, and do not believe they should make any adjustments to ease their inclusion.
EMIS. The routine EMIS contains data on children with disabilities, using ICF-based definitions of disability. Reports are produced on enrolment of children with disabilities.	*EMIS.* There are some data on children with disabilities in the school system, but it is characterized by medical diagnosis. Reports are produced on enrolment of children with disabilities.	*EMIS.* There are some data on children with disabilities in the school system, but it is characterized by medical diagnosis. No reports on enrolment of children with disabilities are produced, except for special schools.	*EMIS.* There are no data on children with disabilities in the routine EMIS.

Indicators for Special Schools

The Convention on the Rights of Persons with Disabilities (CRPD) sets out the goal of inclusive education. Currently, though, in some countries many children are in special schools or self-contained special classrooms within regular schools. Sometimes these children are not considered to be in a particular grade, but only in a special class.

Therefore, the above indicators must also be disaggregated by type of class attended to track the rate of inclusion of children with disabilities in regular schools and classrooms. For example, for enrollment rates the indicators would be:

- Net enrollment rate of children with disabilities in regular classrooms in regular schools.
- Net enrollment rate of children with disabilities in special classrooms or in special schools.
- Adjusted net enrollment rate of children with disabilities in regular classrooms in regular schools.

Since children in special settings are often in mixed-grade classrooms, it will often not be feasible to generate adjusted net enrollment rates for children in those settings. An exception is schools that are specifically for deaf children, which often do have normal grade structures.

Once again, because of the different propensity of children with different types of disabilities to be sent to a special setting, not disaggregating by type of disability could hide some important trends relating to particular barriers preventing children from attending school.

Institutions

In some countries, a significant number of children with disabilities may be living in institutions. Sometimes these are explicitly institutions for children with disabilities; sometimes they are referred to as orphanages. As noted earlier, many may also be living in juvenile detention centres.

Administrative records should be kept on the number of children not attending school who are living in these circumstances. Studies of these populations can then be used to make estimates of how many of these children have disabilities.

Leveraging to Improve Data Systems

Finally, as part of developing the CMF and implementing the Global Initiative on OOSC, efforts should be made to improve data systems on disability. This can be done in a variety of ways:

- Undertake a situational analysis of the barriers to education using both qualitative and quantitative techniques.
- Review existing sources of survey and administrative data in order to identify gaps in information on children with disabilities and the environment.
- Develop proposals for filling the data gaps necessary to address the barriers and bottlenecks found in the situational analysis, and for improving quality of data.
- Incorporate the suggestions for making EMISs more inclusive contained in UNICEF's Guide to EMIS and Disability.

VI. Summary

The world has achieved substantial success in raising the numbers of children with access to education, but much work remains to be done. More and more, the children who are still out of school face barriers specific to their situation. This is especially true for children with disabilities, who are significantly over-represented among OOSC. In order to address their situation, special attention must be paid to the challenges in collecting data on these children so that policies to fulfill their right to an education can be developed, implemented and then monitored for their effectiveness.

Moreover, it is essential when considering children's schooling to think beyond primary and secondary school to ECI, because of its particular importance to children with disabilities' ability to succeed and remain in school.

Collecting data on children with disabilities poses a number of challenges, ranging from shame and stigma to the different institutional and special arrangements that children with disabilities find themselves in. In addition, when thinking of data on children with disabilities it is important to think beyond prevalence in order to link data on children with disabilities to information on the barriers to schooling that they face, be they demand-side, supply-side or policy barriers. It is only by connecting data on children with disabilities with the barriers in the environment that cost-effective policies can be developed.

Until recently, the availability of data that allows this has been very limited. Recently, though, it has begun to be developed. UNICEF and the WG, for example, have developed questions on childhood disability, and are also developing questions on environmental indicators. This booklet has offered guidance on how to evaluate and use those data when they exist, as well as suggesting some practical steps for beginning to acquire essential information when it does not. Whatever approach is taken, it will be important to leverage all existing data systems, and take a systemic approach to gathering information on children with disabilities who are not in school.

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Glossary of Terms

Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol ([A/RES/61/106](#)) was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007. There were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and one ratification of the Convention. This is the highest number of signatories in history to a UN Convention on its opening day. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional integration organizations. The Convention entered into force on 3 May 2008.[23] For more information visit: http://www.un.org/disabilities/

Disability. According to Article 1 of the CRPD, persons with disabilities include "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

Education Management Information System. An EMIS consists of a process of collecting, aggregating and reporting school-based data. It includes data-collection forms and a system for the distribution and collection of those forms; a method of entering those data electronically; the creation of indicators at the school, district and national level; and finally a set of standardized reports using these data that remain consistent over time in order to track the performance of the education system.

Inclusion is where there is recognition of a need to transform the cultures, policies and practices in school to accommodate the differing needs of individual students, and an obligation to remove the barriers that impede that possibility.

Inclusive Education is "a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the state to educate all children."[24]

Institution is a facility, usually large and state run, that provides services either in a hospital setting or as part of a penal system.

Special Schools are schools specifically designed for children with disabilities. They may provide services to all children with disabilities, or children with certain types of disabilities. They often do not follow the general education curriculum.

Washington Group is a group established by the UN Statistical Commission to come up with recommendations for improved internationally comparable measures of disability for monitoring and evaluation. Its membership is open to the national statistical offices of all UN member countries. The UN Statistical Commission names its groups after the first city they meet in, hence the name Washington Group. Their website is http://www.cdc.gov/nchs/washington_group.htm

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Additional Resources

- **UNICEF, State of the World's Children: Children with Disabilities, 2013**. Can be found at

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- **UNICEF/UIS, Framework for Monitoring Out-of-School Children and Adolescents in the ECA Region, 2014**.

- **UIS webpage on OOSCI**, http://www.uis.unesco.org/Education/Pages/out-of-school-children.aspx

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