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Identifying disability in household surveys: Evidence on education access and learning for children with disabilities in Pakistan

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Key messages

1. It is vital and feasible to adopt approaches that identify children with different types and severity of disability in surveys in order to understand the challenges they face in their schooling experiences, and identify strategies to support them.
2. Inclusive education in a context like Pakistan needs to be understood broadly, taking into account disadvantages arising from the intersection of disability, poverty, gender, location and other factors.
3. Evidence from our new data shows that children with disabilities are attending mainstream (government and private) schools. It is important to identify strategies to support their learning in these settings.

Introduction

This policy brief presents key findings from data on education of children with disabilities in Pakistan with respect to both access and learning. It draws on data from on-going research as part of the ESRC-DFID funded Teaching Effectively All Children (TEACH) project, along with data from ASER Pakistan.

The aims of this policy brief are to:

- Outline current approaches to identifying children with disabilities in surveys in Pakistan, with the aim of understanding their schooling experiences.
- Present emerging findings on education and disability in Pakistan.
- Highlight lessons from these data to inform approaches to identification of children with disabilities.
- Identify strategies to improve education provision for children with disabilities in Pakistan's primary schools.

Identifying disability through surveys in Pakistan

Identifying children with disabilities is not straightforward. Until relatively recently, information on the prevalence of disability in large scale surveys in Pakistan, as elsewhere, relied on questions which were unlikely to collect accurate information on disability. For example, the 1998 census asked the question, "Do you suffer from any type of disability: physical disability, visual impairment, hearing impairment, mental disability, or overlapping?"¹ Such questions were extremely limited in their usefulness as they understood disability as a binary category, rather than reflecting the diversity in severity and types of disabilities. Also there was likely to be high underreporting as labelling individuals as 'disabled' in questions could be stigmatising in many societies.

In the National Census 2017, a similar question focusing on the presence or absence of disability has been incorporated. The question on disability was introduced after much lobbying² by disability groups, and included under the 'sex' column of the census form. Initially the census form had allotted three codes: '1' was for male, '2' was for female and '3' was for transgender residents. On the orders of the Supreme Court, two additional codes were added to the code sequence: '4' for disabled man, '5' for disabled woman and '6' for disabled transgender person. The incorporation of a complicated question in mid-cycle of census collection has raised concerns around reliability of the data gathered.

As an alternative to this approach, disability prevalence can also be established through assessment and diagnostic measures undertaken by health professionals. This approach was used in the 2012 Pakistan Alleviation Fund – Disability Evaluation Report. The sample survey, conducted after the 2005 earthquake, covered 80,000 households in 7 districts. However this approach is expensive and difficult to undertake on a large scale, given the paucity of trained health professionals in many developing contexts.

There has been considerable progress in recent years in developing internationally-recognised approaches to identifying people with disabilities in surveys based on approaches that do not involve medical diagnosis. These have been developed by the Washington Group on Disability Statistics, established under the United Nations Statistical Commission to "...Address the urgent need for cross-nationally comparable population based measures of disability."³

Questions on disability developed by the Washington Group represents the most recent thinking around disability and draw support from the United Nations Convention on the Rights of Persons with Disabilities. Here disability is defined more broadly as, "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" (UNCRPD, 2007, p.4).⁴

Over the years, the Washington Group has developed three sets of questions:

- 1) The Washington Group Short Set of Questions on Disability: a short set of questions focused on assessing functioning of adults.
- 2) The Extended Set of Questions on Functioning: a long set of questions focused assessing functioning of adults.
- 3) Child Functioning Questions: these are for two different age categories (i) for children under 5 years (ii) for children 5 to 17 years. All questions are asked of child's parents/ primary care givers. To focus the respondent on the functioning of their own child with reference to that child's cohort, where appropriate, questions are prefaced with the clause: "Compared with children of the same age..."

Overall, questions developed by the Washington Group provide a simple, sensitive and nuanced way of capturing disability, even in contexts where there are concerns that stigma could prevent direct reporting of disability. The questions provide the opportunity for international comparability, and have been developed using a rigorous methodology.⁵

Versions of the Washington Group questions have been adopted to identify children with disabilities in surveys in Pakistan, including as part of the citizen-led assessment (ASER) data collection, and the Teaching Effectively All Children research project (Table 1). The ASER and TEACH household surveys, for example, each identify a range of difficulties that children might face (Table 2). As shown in these tables, ASER uses the Washington Group set of Short Questions supplemented with questions which ask about child's ability understand and remember things, while TEACH uses the full set of questions listed in the 'Child Functioning' for children aged 5 to 17 years. In addition, the World Health Organization has undertaken a Model Disability Survey pilot using Washington Group questions in Tehsil *Pendi Geheb*, which is currently under preparation.

Table 1: ASER Pakistan and TEACH approaches to identifying disability

	ASER	TEACH
Source for the Questions on disability	Uses the set of the 'Short questions' developed by the Washington Group, together with questions on 'understanding' and 'remembering' taken from an earlier version of the Washington Group's child functioning set of questions.	Uses the full set of questions listed in the 'Child Functioning' for children aged 5 to 17 years.
Respondents	Parents/ carers are the respondents.	Parents/ carers are the respondents.
Types of questions asked for one type of functioning difficulty/disability	Does your child have difficulty seeing, compared to children of the same age a. No difficulty in seeing b. Yes- some difficulty c. Yes- a lot of difficulty d. Cannot see at all	Does [NAME] wear glasses? Yes-1, No-0. When wearing glasses, does [NAME] have difficulty seeing? 1. No Difficulty 2. Some Difficulty 3. A lot of difficulty 4. Cannot do at all Does [NAME] have difficulty seeing? 5. No Difficulty 6. Some Difficulty 7. A lot of difficulty 8. Cannot do at all
Sample (children aged 8-12) ⁶	22,000 children across Punjab province	1,549 children in 3 districts in Central Punjab

Table 2: Types of functionings included in ASER Pakistan and TEACH surveys

	ASER	TEACH
Seeing	✓	✓
Hearing	✓	✓
Walking	✓	✓
Self-care	✓	✓
Understanding of child's speech (within and outside the household)	✓	✓
Learning		✓
Remembering	✓	✓
Controlling behaviour		✓
Focusing		✓
Routine (accepting changes)		✓
Making Friends		✓
Worry		✓
Sad		✓

What is the prevalence of disability in Pakistan?

Key messages:

- Previous surveys suggest that prevalence rates for disability range from 1% to 2%. The TEACH survey suggests that prevalence rates are higher, with at least one in ten children experiencing difficulties that have a significant impact on an aspect of their daily functioning.
- TEACH data also identified that childhood disability and household poverty appear to be related.
- In order to do meaningful disaggregation of data a large sample size is needed. This enables better understanding of how different types of disabilities intersect with other variables such as gender, poverty, location and ethnicity.

Identifying the prevalence, type and severity of disability in Pakistan

Approaches that have used direct questions on disability, as in the Pakistan national census, have been found to result in low prevalence rates (WHO, 2011 p. 4).⁷ While approaches using a functional approach to disability, as proposed in the Washington Group questions, identify higher rates of disability prevalence. Comparing moderate to severe disabilities across these different sources identifies prevalence rates ranging from around 1% to 11% (Table 3).

The 1998 National Census in Pakistan, asking a binary yes/no question, identified a prevalence rate of just 2.5%. The Pakistan Poverty Alleviation Fund's Survey in 2012 was based on medical diagnosis similarly identified a low prevalence rate of around 2%. ASER also found low prevalence rate of less than 1%. This could be explained by the fact that it used a sub-set of the Washington Group questions (see Table 2).

Using the Washington Group child functioning questions, TEACH estimates a prevalence rate of 11.2% among children. This is considerable higher than in other surveys in Pakistan. It is, however, more in line with global figures estimated by the World Health Organisation. The World Disability Report notes that "over a billion people (or about 15% of the world's population) were estimated to be living with disability" (WHO, p. 53).

Table 3: Prevalence rates of disability in censuses and surveys in Pakistan

Survey or census	Age range in estimate	Prevalence rate of moderate to severe disabilities
Population Census 1998	Total population	2.5%
Pakistan Poverty Alleviation Fund - Disability Evaluation Report 2012	Across different ages	2%
Annual Status of Education Report 2015	8-12 year olds	1%
Teaching Effectively All Children	8-12 year olds	11.2%

While TEACH used the full set of child functioning questions, the estimate in Table 3 excludes questions related to children being 'sad' or 'worried'. Including these questions increases the prevalence rate to 16% (Table 4). Higher reporting on these questions has also been found by the Washington Group in other countries. As a consequence, the Washington Group has adapted the questions to introduce the word 'very'. For example, in the earlier version the question around worry was framed as: How often does (name) seem anxious, nervous or worried? Would you say: daily, weekly, monthly a few times a year or never? Now the question reads: How often does (name) seem very anxious, nervous or worried? Would you say: daily, weekly, monthly a few times a year or never? It is hoped that this change will provide a more reliable picture on difficulties in these areas of functioning.

We undertook factor analysis to ascertain whether some of the functionings were more closely associated with each other, and should be clustered together in the analysis. Based on factor analysis of the 13 different functionings of the Child Functioning Module, we noted that all of the dimensions were closely related with the exception of ones associated with 'sad' or 'worried'.⁸ Given concerns around the validity of the questions associated with being sad or worried in other countries, combined with the results of factor analysis of our data which also raises questions about what is being measured, we have chosen to exclude these functionings from the analysis that follows. We recognise, however, that questions related to children's mental health are extremely important, and further work to identify robust ways to include information on this in surveys will be vital.

Given the close association between the other functionings (excluding those associated with being sad or worried) in the factor analysis, it is appropriate to cluster these together in the analysis that follows (see Table 4 for prevalence rates). This close association is perhaps not surprising given that children who face difficulty in one area, such as seeing are also likely to have difficulties in walking without the required aids and appliances.

Table 4: Prevalence of of disability in the TEACH survey

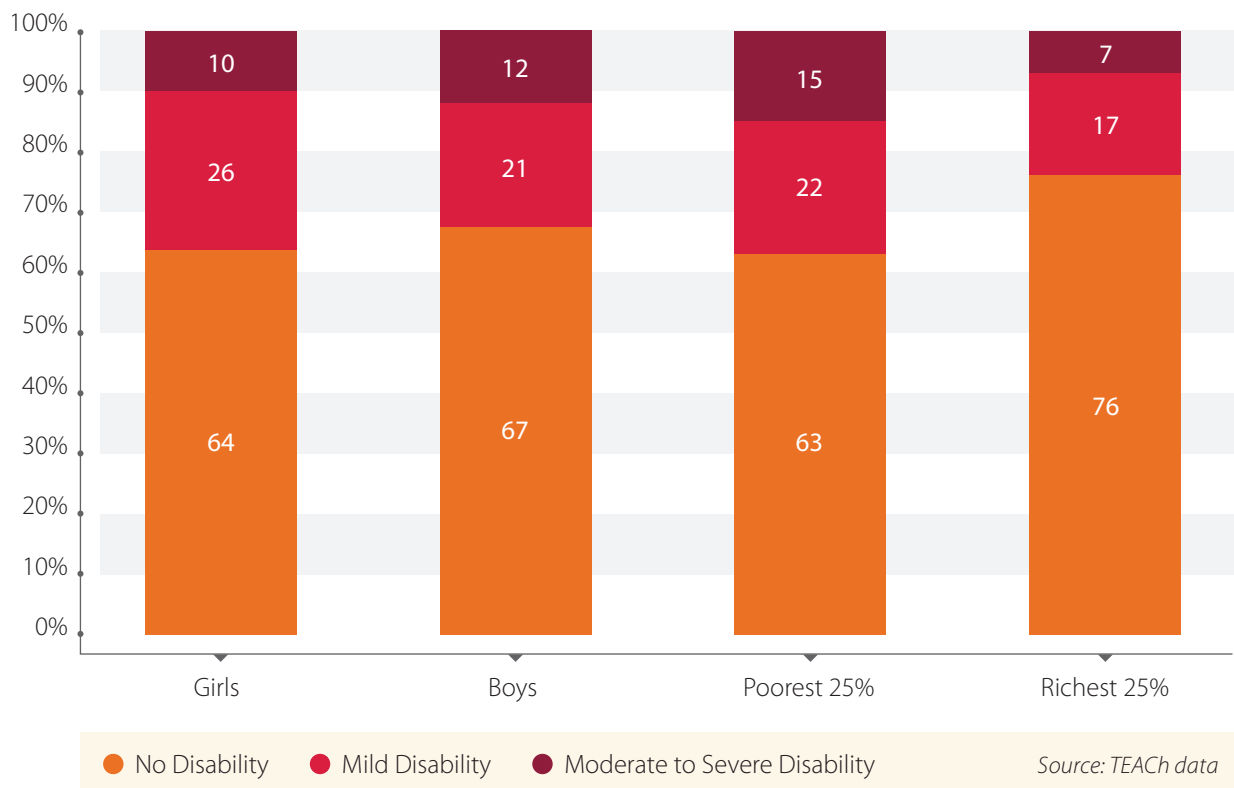
	No Disability		Mild Disability		Moderate to severe	
	n	%	n	%	n	%
Total (including all 13 functionings)	876	56.6	426	27.5	247	15.9
Worried and sad only	1292	83.4	155	10	102	6.6
Total excluding worried & sad	1017	65.6	359	23.2	173	11.2

Source: TEACH data

Identifying intersections between disability and other forms of disadvantage, such as gender and poverty

Data from the TEACH survey suggests that prevalence rates for disabilities for girls and boys are similar in the sample areas (Figure 1). However, it is noticeable that children with disabilities are more likely to be in poorer households: around 15% of children in the poorest quartile of the sample are reported to face moderate to severe difficulties compared with 7% of those in the richest quartile. It should be noted that this translates into relatively small numbers overall (for example, 24 children from the richest quartile in the sample are reported to have a moderate to severe difficulty), so caution is needed in the analysis. Even so, the larger ASER Pakistan survey shows a similar pattern for gender and poverty intersections with disability.

Figure 1: Intersection of disability with gender and poverty



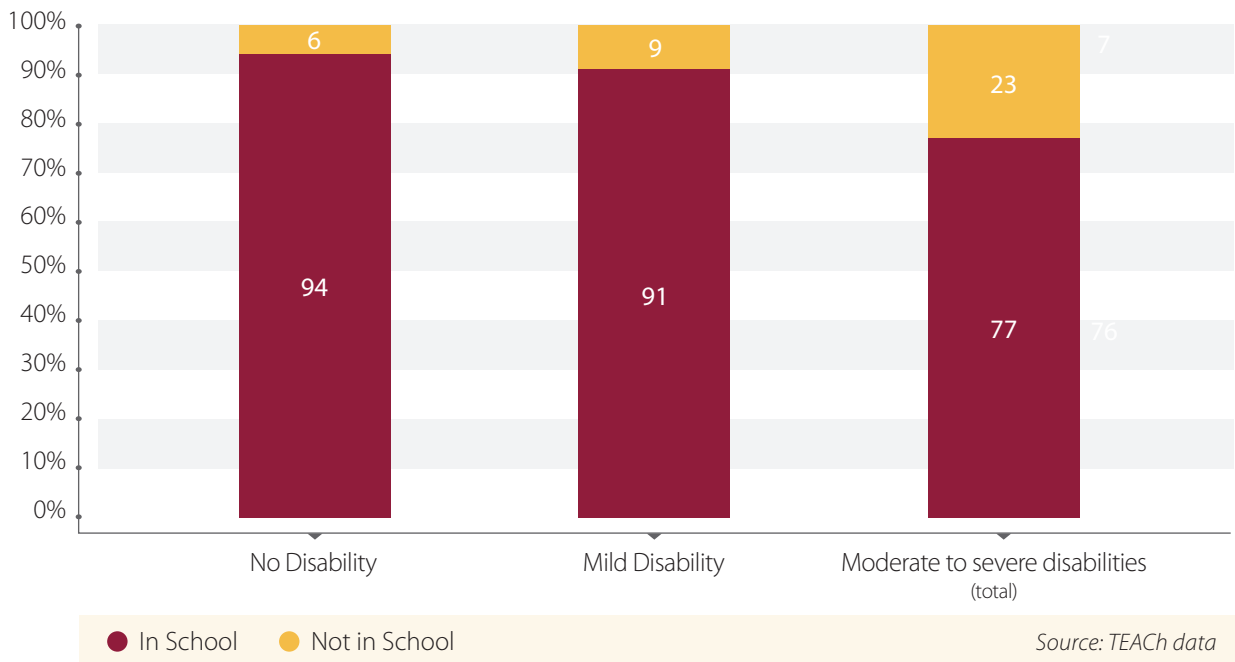
Are children with disabilities in school?

Key messages from TEACH data:

- A large proportion of children with disabilities are in mainstream schools, even though they are more likely to be out of school than their peers.
- Children with moderate to severe disability are most likely to be out of school.
- There is variation in school attendance according to type of disability: children with communication and physical disabilities are most likely to be out of school.
- Some children with disabilities are attending private schools, although at a slightly lower rate than their peers.
- Private school enrolment is more likely amongst boys with disabilities, while girls with disabilities are more likely to be out of school.

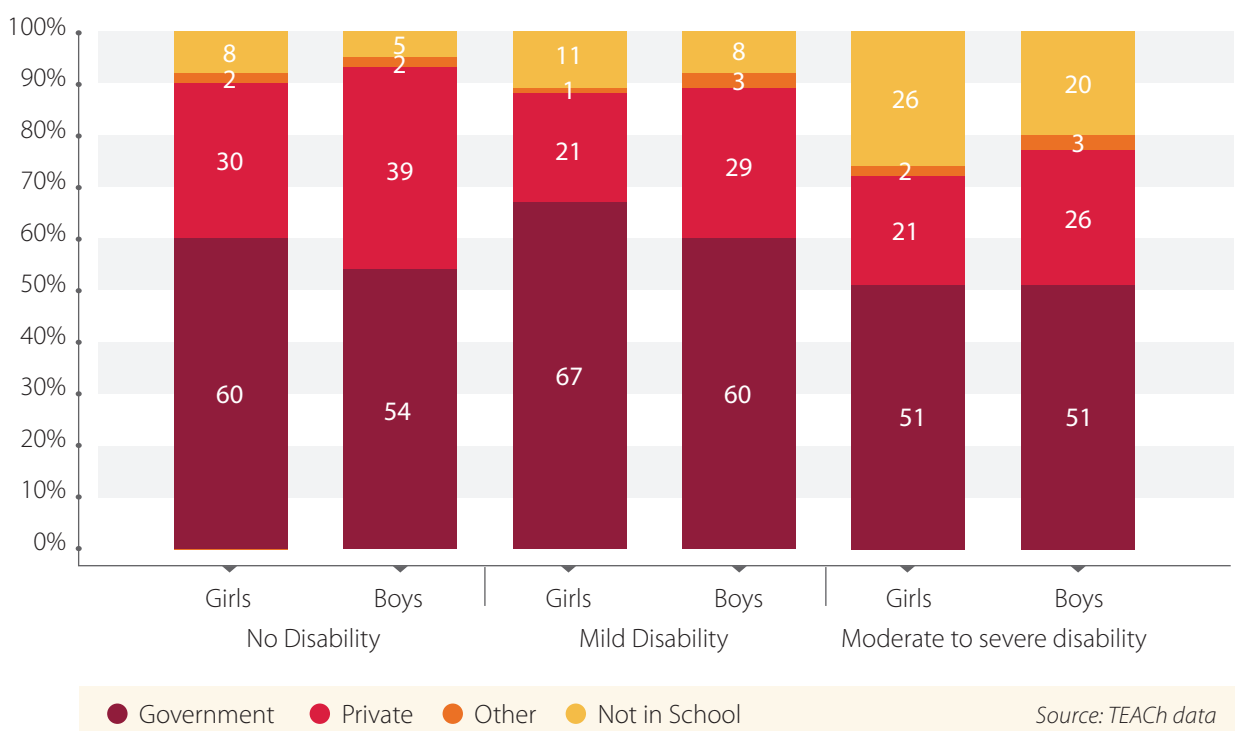
Data from the TEACH survey identify that there are variations in school enrolment depending on severity and type of disabilities. It should be noted that Central Punjab, the area selected for the TEACH survey, has higher levels of enrolment than some of the more disadvantaged areas of the country. For example, according to ASER Pakistan data, Central Punjab has an overall enrolment rate of 90%, compared with 83% in Southern Punjab, or 66% in Sindh. In the TEACH sample, the vast majority of 8-12 year olds without disability were in school, with only around 6% out of school (Figure 2). By comparison, around 23% of those identified with moderate to severe disabilities were out of school. Interestingly, a significant proportion of those facing difficulties in walking are out of school, although the sample size is small: nine out of 15 children reported to have moderate to severe difficulties with walking are out of school. ASER Pakistan data also find a relatively high proportion of children facing physical difficulties are out of school.⁹ This could suggest the lack of basic adapted facilities in schools, such as ramps, aids and appliances, adapted teaching and learning materials which might prevent these children from accessing schools and the curriculum.

Figure 2: Children out of school by severity of disability



In this context where a reasonable proportion of children are in school, including those with disabilities, it is also notable that some children identified with disabilities are in private schools (Figure 3). The proportion in these schools is higher for boys, suggesting that parents are more likely to be willing to invest in their son’s education whether or not they have a disability. By contrast, a larger proportion of girls, irrespective of their disability status, are likely to be out of school. Even so, the fact that around one quarter of boys and one-fifth of girls with moderate to severe disabilities are found enrolled in private schools deserves further investigation. It should again be noted that the absolute numbers in these categories is very low given the small sample sizes of the sub-categories, so caution is needed in drawing policy conclusions directly from these data.

Figure 3: Type of school attended by disability and gender



Are children with disabilities learning?

The TEACH survey included assessment of children using ASER and Young Lives tests.¹⁰ The test was administered to children aged 8-12 years old in the household, regardless of whether the child was in school or not. Drawing on the ASER test, the data suggest that learning outcomes for children with disabilities are lower than those for children without disabilities for both literacy and numeracy, particularly for those with moderate to severe disabilities (Figure 4a). However, it is notable more generally that the ability of children to read a story or do division is low for all children aged 8-12 years in the sample, regardless of whether they have a disability. Similar results were found using the Young Lives survey. These low levels of learning for all children suggest that there is a need to improve the quality of education for all children. At the same time, the greater disadvantage for children with moderate to severe disabilities suggests a targeted approach is also needed.

Nonetheless, being in school matters for learning both for children with and without disabilities. The gap in learning is narrower between children with disabilities and those without disabilities who are in school (Figure 4b), compared to their peers who are out of school (Figure 4c).

Figure 4a: Learning of children by severity of disability using ASER test (including children both in and out of school)

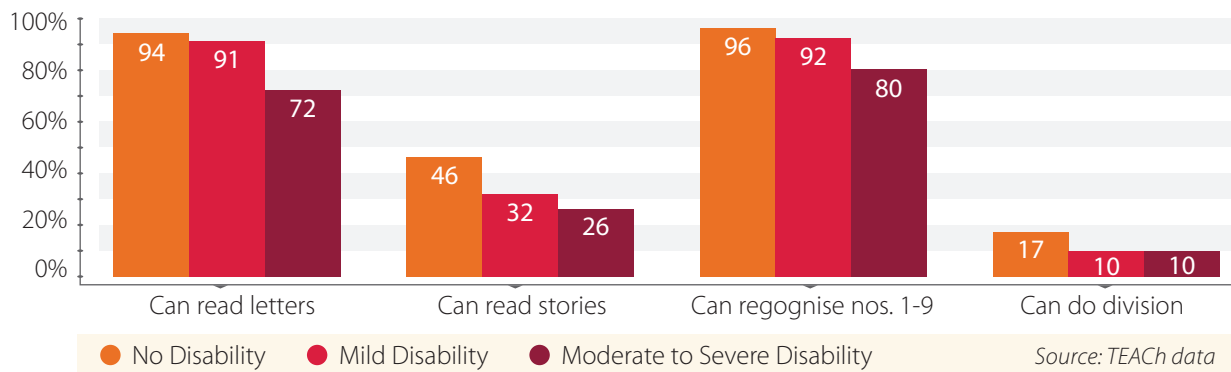


Figure 4b: Learning of children by severity of disability using ASER test (children in school)

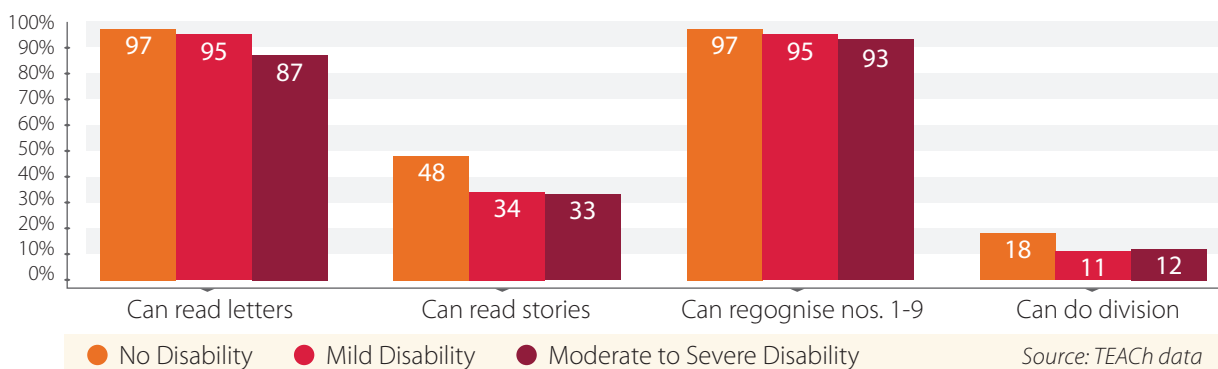
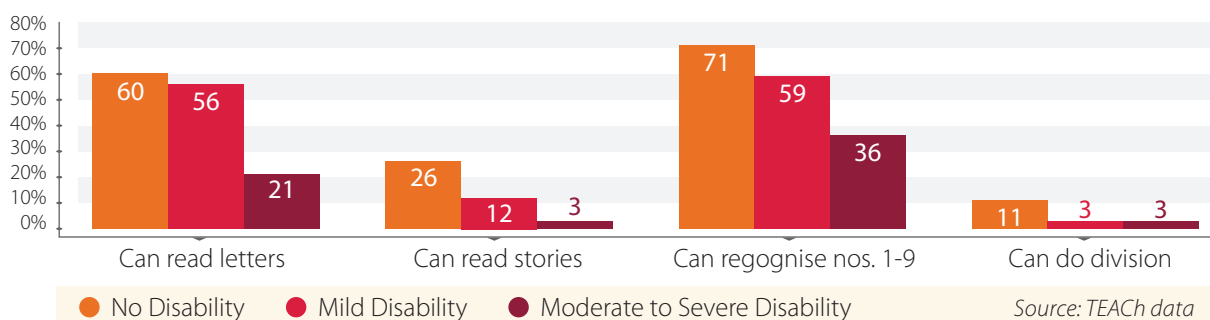
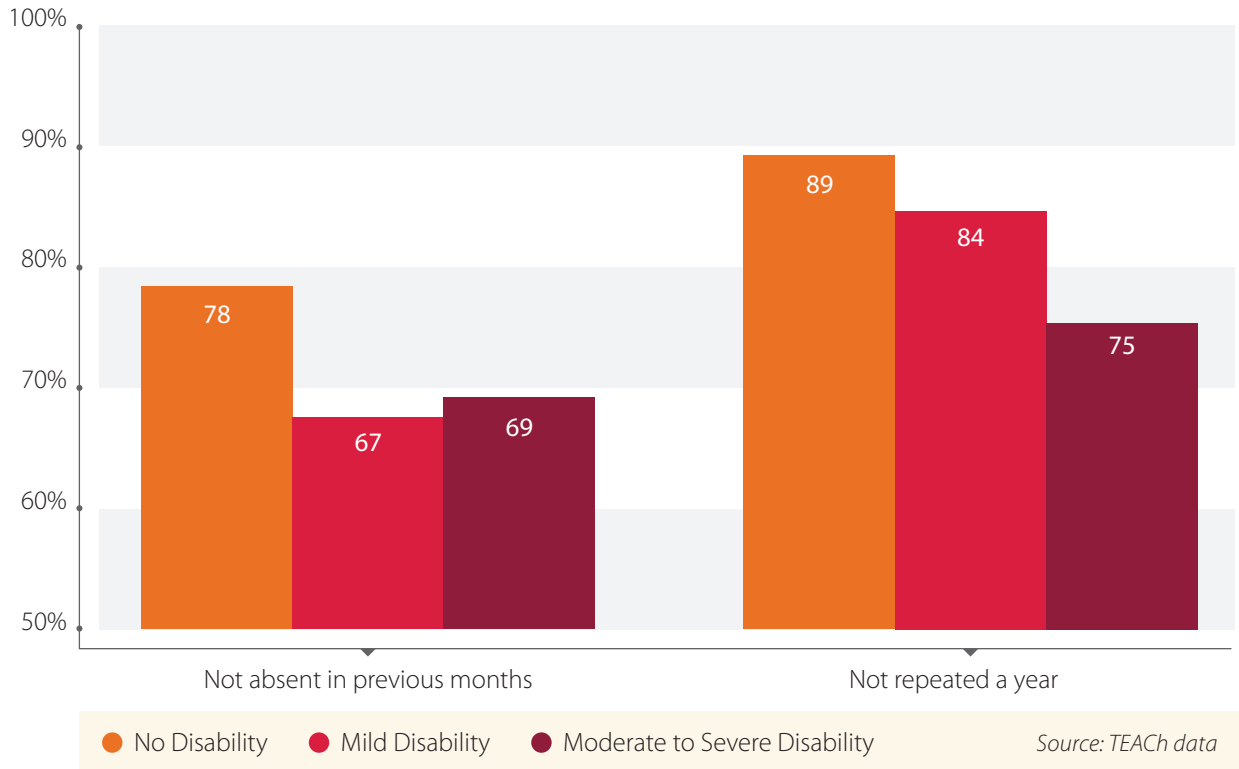


Figure 4c: Learning of children by severity of disability using ASER test (out of school)



For those children in school, children with disabilities are more irregular in their attendance and more likely to repeat classes compared to children without disabilities (Figure 5). They are also more likely to have repeated a year. Their greater likelihood of absenteeism could contribute both to the higher chance of repetition as well as lower learning. As such, the reasons associated with their absenteeism and ways to minimise this deserves further investigation.

Figure 5: Absenteeism and repetition by disability



Key recommendations

Overall our analysis of data on children with disabilities in Punjab provides three key lessons for Pakistan as well as more widely:

(1) Identification of children with disabilities is vital and feasible.

Our TEACH survey shows that it is feasible to incorporate child functioning questions from the Washington Group in household surveys with appropriate training of data collectors to ensure sensitivity and accuracy in the way the questions are asked. These internationally recognised and standardised questions can provide important disaggregated data to understand the schooling experiences of children with disabilities. If introduced in surveys more systematically, these data can allow for comparisons across time and settings. Disaggregation can provide important insights into relationships with poverty, gender, location, ethnicity etc. It is, therefore, important to determine a sufficient sample size in surveys to allow for such disaggregation. Crucially, information gathered using the Washington Group questions can be useful in identifying individuals who would benefit from more rigorous diagnostic processes in order to receive the kind of support that might be necessary to function effectively in their surroundings.

(2) Addressing access and learning of children with disabilities is an important issue for policy.

Our analysis shows that, in the setting of Central Punjab, Pakistan, parents of children with disabilities are sending their children to school. Children with disabilities are attending mainstream schools, and in some cases parents are paying for private education, particularly for boys. While it is not possible to generalise from this setting to other parts of Pakistan, and it is also important to be cautious given sample sizes, the findings do suggest that further consideration is needed to recognise the value that parents appear to place on the schooling of their children with disabilities. This suggests that policymakers need to work together with parents as important partners in identifying solutions to the education of children with disabilities.

(3) Approaches to inclusive learning are necessary to support children with disabilities once they are in school.

Many countries, including Pakistan, have a separate government department with responsibility for the education of children with disabilities. In Pakistan, the Special Education Department functions separately from the Basic Education Department, and has responsibility for special schools¹¹. Given the number of children who are attending mainstream government and private schools, it is vital that there is no separation of the responsibilities between these departments. Rather, these departments need to come together to share expertise in ways that ensures an inclusive learning environment for all children.

A basic first step to include children with disabilities in school is an inclusive infrastructure in schools which such as ramps, provision of aids and appliances and the availability of appropriate teaching and learning materials.¹²

Evidence from the TEACH survey indicates that in Punjab many children with disabilities are getting access to school. This implies that stigma and discrimination might not always be as apparent as feared in relation to school access. However, our survey indicates that children with disabilities who do go to school have very low levels of learning. Hence it is important the children and their teachers are supported. This can be facilitated through changes in the classroom such as seating children appropriately, with those with difficulties in reading the blackboard towards the front, to more systemic changes, such as providing teachers better training, use of adapted teaching and learning materials and even support from specialist professionals. For example, in some states in India, under the Sarva Shiksha Abhiyan (SSA) programme, state governments have appointed Inclusive Education Resource Teachers to support teachers in government schools who have children with disabilities in their class. These teachers are trained special educators and support teachers with the development of Individualised Educational Plans and advice on effective teaching strategies¹³.

Endnotes

1. <http://www.ilo.org/surveydata/index.php/catalog/960/study-description>
2. <https://tribune.com.pk/story/1355032/sc-seeks-explanation-pbs-neglecting-persons-disabilities-census/>
3. Washington Group on Disability Statistics, details available at: <http://www.washingtongroup-disability.com/>
4. United Nations Convention on the Rights of Persons with Disabilities http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/61/106
5. Details of the field and cognitive testing undertaken by the Washington Group is available at: <http://www.washingtongroup-disability.com/methodology-and-research/testing-methodology/>
6. The numbers for ASER in this note – for comparison – are for 3 districts and for 8-12 year olds only. The complete sample for ASER is 60,000 (3 – 16 year olds) across the 4 provinces.
7. World Report on Disability. http://www.who.int/disabilities/world_report/2011/report.pdf
8. Results of the factor analysis are available from the authors on request.
9. Rose, P., Sabates, R., Alcott, B., & Ilie, S. (2016). Overcoming inequalities within countries to achieve global convergence in learning. Background paper for The International Commission on Financing Global Education Opportunity Report.
10. See <http://aserpakistan.org/tools> for ASER tools and <http://younglives.qeh.ox.ac.uk/what-we-do/access-our-data> for information on Young Lives tools (TEACH adapted Young Lives learning assessment tools from India for use across both countries).
11. Moving from the margins. Mainstreaming persons with disabilities in Pakistan https://www.britishcouncil.pk/sites/default/files/moving_from_the_margins_final.pdf
12. Singal, N., Ware, H. and Khanna-Bhutani, S. (2017) Inclusive Quality Education for Children with Disabilities. Report prepared for the World Innovation Summit for Education. <https://www.wise-qatar.org/2017-wise-research-inclusive-education-children-disabilities>
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