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Promoting access to education for disabled children in low-income countries: Do we need to know how many disabled children there are?

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A R T I C L E   I N F O

A B S T R A C T

Poor people are most likely to be disabled, and the exclusion of disabled people from education means that they are also more likely to remain poor. Despite calls for better data to inform the extension of education for disabled children, data in this field remain weak. This paper asks whether a national survey of disability prevalence is the best starting point when promoting the educational inclusion of disabled children in low and middle-income countries. The paper analyses what information is needed about disability in education systems, and also analyses difficulties with measuring childhood disability. The paper concludes that the most pragmatic and ethical way forward is to make the most of knowledge we already have to develop and continue learning from existing provision.

1. Introduction

Disabled people[1] are among the poorest of the poor (DFID, 2000; Ghai, 2002). Poor people appear most likely to be born with or acquire an impairment due to relatively high exposure to disease and injury, and often inadequate healthcare and nutrition (DFID, 2000; Solarsh and Hofman, 2006). Disabled people also often remain or become poor. Alongside difficulties in accessing healthcare and other services, disabled people's exclusion from education is argued to contribute to further economic and social exclusion in adult life (Rust and Metts, 2007). Disability is thus 'both a cause and consequence of poverty' (DFID, 2000:1). This has led to growing calls for disabled people to be included in development (Hulme and Ibrahim, 2011).

Disability is systematically related to poverty in countries across the economic spectrum but levels of impairment appear highest in low-income countries (UNESCO, 2010). Braithwaite and Mont (2008) estimate that around 20% of the world's poorest people have some kind of impairment, with four hundred million of these living in low-income countries. For example, rates of

sensory and mobility impairment are high in many African countries (Solarsh and Hofman, 2006). Some of the poorest states are those affected by conflict, which can directly cause impairment through injury, and also exacerbate the socio-economic conditions that increase impairment (UNESCO, 2010). Sumner (2010) however, questions whether a focus on inequality is needed to reduce poverty rather than a focus largely on national economic growth. Addressing inequality will arguably have a greater impact on poverty because around two-thirds of the 'new bottom billion' of the world's poorest people are in middle-income countries.

Although information is limited, disabled children and youth appear to have very unequal access to education compared to non-disabled peers (Bines and Lei, 2011). In his analysis of data from eleven household surveys, Filmer found that 'the [schooling] deficits associated with disability are large compared to other sources of inequality' (2005:14). Being disabled appears to at least double the chance of never enrolling in some African countries and to significantly increase the chance of 'dropping out' (Hunt, 2008; UNESCO, 2010). As more children participate in education then the social and economic exclusion of those who do not becomes more pronounced (Hossain, 2010).

Rose and Dyer (2008) argue that the precise means by which education reduces poverty are often unclear, although poor people frequently pursue education as a way out of poverty. Disabled adults, for example, have long been involved in supporting the education of disabled children, to counter in the next generation the exclusion they themselves faced (Anand, 2009; Kimani, 2012; Sutherland, 1981). Rose and Dyer note the limitations of a human capital view of education's role in addressing poverty. They argue

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[1] This paper uses the terms 'disabled children', 'disabled people' etc. as these are used by the British Council of Disabled People which represents large numbers of disabled people in the country in which it is written. These terms recognise that people are disabled by society. In other contexts 'people with disabilities' is sometimes the preferred term, emphasizing that people with impairments are 'people first'.

that education is important for 'developing female voice and agency' (2008:79), an educational outcome with relevance for other marginalised groups such as disabled people. Two recent empirical studies investigated the effects of education through life history interviews with disabled higher education students and graduates. The studies focused on agency and found education to be transformative of disabled people's social and economic situations (Hammad and Singal, 2011; Morley and Croft, 2011).

Education is therefore thought to have the potential to contribute to breaking the connection between disability and poverty, but, conversely, to exacerbate poverty where it excludes disabled people. In the light of this, under article 24 of the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), disabled children have the right to 'an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live' (UN, 2006). In the push for Education for All it has been recognised that the second United Nations Millennium Development Goal (MDG) cannot be met without the inclusion of disabled children in schools (UN Secretary General, 2007) and so the 2010 Education for All Global Monitoring Report (GMR) on marginalisation stated that the 'starting point' for extending education for disabled children should be 'a credible needs assessment based on a national survey of the prevalence of disability' (UNESCO, 2010:203). There has, however, been long-standing recognition of the difficulty of collecting useful data on how many children have impairments that affect their access to school and their success once enrolled (Ainscow, 1999).

Eide and Loeb (2005) described data on disability in general to be particularly weak in low-income countries. Metts (2004) calculated that a prevalence of 7–10% was at 'very highest end of the range' of likely estimates but that the 1% figure used by UNDP was an underestimate. More recently, Mont (2007) and Hulme and Ibrahim (2011) stated that the widely quoted figure of 10% was very much an estimate, while the first 'World Report on Disability' in 2011 raised estimated prevalence to 15% (WHO/World Bank, 2011). Much disability is associated with aging however, and so, prevalence varies considerably between age cohorts. For inclusion in formal schooling, the prevalence in younger population cohorts is therefore of more significance than overall prevalence, although this is not always recognised. With particular regard to education, existing data sets were considered 'remarkably weak' in an Education For All Inclusive Education Flagship paper in 2004 (UNESCO, 2004). Several background papers dealing specifically with disability for the 2010 GMR comment on the widely varying estimates of disability prevalence in school-aged populations in particular countries (Croft, 2010) which suggest inaccuracies in measuring prevalence. Data from UNICEF's State of the World's Children report give starkly differing estimates of childhood disability prevalence from countries which would be expected to have similar levels. For example, 3% for Chad compared to 48% for the neighbouring Central African Republic[2] (UNICEF, 2010) – countries with very similar scores on the 2009 Human Development Index, both considered 'conflict-affected' (UNESCO, 2010). The World Disability Report (WHO/World Bank, 2011) estimates that there are between 93 and 150 million disabled children under 14 years, with a global prevalence for moderate and severe disability in this age cohort of 5.2% (6.4% in Africa and 5.3% in South East Asia). The global prevalence for children who are severely disabled is however estimated to be only 0.7%.[3]

In the face of this lack of clear information there have been ongoing calls for more robust disability statistics (Eide and Loeb, 2005) and article 31 of the CRPD (2006) requires states to collect statistical information on disability. There have similarly been continuing calls for better educationally specific data on disability from a range of international development agencies (UNESCO, 2004; McLaughlin and Ruedel, 2005; WHO/World Bank, 2011). Carr-Hill (2012) has similarly noted the inaccuracy of figures on out-of-school children more generally, and the difficulties of finding and counting the children of marginalised communities. This paper addresses the impasse created by continuing calls for better data alongside recognition of the continuing weakness of data generated. It asks whether a survey of prevalence is a necessary and feasible place to start when extending education to disabled children who are likely to be some of the poorest citizens, now or in the future. While education is broader than schooling, this paper is limited to looking specifically at access to formal education as conceived in the second MDG and the CRPD.

2. What data are needed?

2.1. Uses of disability data

Data on disability are potentially useful at all stages of the process of including disabled children in schooling. In the initial stages of advocating for anti-discriminatory legislation, policy and funding, comparative statistics are seen as 'ammunition' (Albert et al., 2005) to get disability on national and international political agendas (Eide and Loeb, 2005; Fujiura et al., 2005). The educational status of disabled children and youth can be compared to non-disabled populations, and comparative statistics can also highlight international and intra-national inequalities including trends in educational access between different populations of disabled children, for example by ethnicity, region or type of impairment (UNESCO, 2010).

At the policy development stage, disability data can help identify the background characteristics of groups of excluded children and those 'at risk' of exclusion and thus inform understanding of the barriers to their inclusion, leading to the planning and implementation of appropriately targeted interventions (CRPD, 2006; UNESCO, 2010; World Vision, 2007). Data that are disaggregated on a number of dimensions are important as disability intersects with other structures of inequality, such as gender (Rousso, 2003) and ethnicity (de Beco et al., 2009). The over- or under-representation of certain groups in specialist provision for disabled children (disproportionality) is well-documented at least in some contexts. For example, Robson and Evans (2003) cite Ethiopian research that found that the male/female ratio among disabled students in special settings was 140:1. Data can therefore assist in demonstrating transparency and accountability in the distribution of resources to services, groups, and individuals (Eide and Loeb, 2005). Finally, data can be collected to monitor and evaluate the impact of interventions (UNESCO, 2004; Modern et al., 2010; CRPD, 2006). The lynchpin of all these potential uses of disability statistics however, is the provision of education for disabled children. There is concern that 'relatively positive' (Modern et al., 2010) national and international disability legislation and policy are failing to deliver sufficient change in education systems. This paper's necessarily limited scope will therefore be on the information needed for planning and implementation.

2.2. Are disability-specific reforms needed?

How disability is defined is important as this locates the action required to address the injustice associated with it (Albert, 2004).

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[2] Table 9, Child protection, State of the World's Children: special edition (UNICEF, 2009) http://www.unicef.org/arabic/rightsite/sowc/pdfs/statistics/SOWC_Spe-c_Ed_CRC_Statistical_Tables_EN_111309.pdf (accessed 15.1.12).

[3] Source: Table 2.2 (WHO/World Bank, 2011) based on Global Burden of Disease estimates for 2004.

The individual/social model analysis of approaches to disability has considerably influenced debates on extending education for disabled children (Croft, 2010), with many writers arguing for a shift from interventions focused on individuals' impairments to a social model analysis of the barriers that construct disability within education systems (DFID, 2000; Pinnock and Lewis, 2008; Rieser, 2008). Stubbs and Lewis note that debates around special and inclusive education have generally moved on from issues around categorising learners, to the location of education (e.g. local mainstream school, specialist unit or more distant special school), and on towards issues of 'power, participation and achievement in learning' (2008:46). While the social model is still considered useful for highlighting the oppression including poverty faced by many disabled people (Albert, 2004), recent debates in disability theory have recognised the interaction between disabled people and their varying contexts which lead to diverse and evolving experiences of disability (Ghai, 2002; Lang, 2007; Meekosha, 2008; Shakespeare, 2009). Therefore, in order to include disabled children in schooling, information will be needed not only on characteristics of children but also on the impact of disability in their lives (WHO, 2002).

In seeking to educate disabled children, an important question is the extent to which characteristics of these children tell us anything useful. Whether from intuitive appeal (Florian and Kershner, 2009) or by force of cultural habit, it is commonly assumed that disabled learners need specific provision such as specific teaching approaches, different or additional curriculum content, particular facilities, materials or learning contexts, and that these will be related to categories of impairment (Norwich, 2008). There are essentially two broad positions in answer to the question of whether there should be educational interventions aimed specifically at disabled children such as 'special teaching for special children' (Lewis and Norwich, 2005), that would require detailed knowledge of school-age disability prevalence.

In the first position it is argued that general quality improvement, i.e. education that recognises and responds to the diversity of learners (Booth, 2000), is 'child-friendly' and even 'child-seeking' (UNICEF, 2009), will by definition include disabled children. In this case, for planning and implementing educational provision we do not need to know the overall number of disabled children, or numbers of children with particular impairments, although this information might be useful for other purposes (see Section 2.1). Klassen et al. describe Australian 'low achievement/non-categorical approaches, where intervention is provided to all low performing students, irrespective of the nature and aetiology of the academic deficit' (2005:298) based on the assumption that difficulties are often transient and appear and disappear in interaction with the educational context. Writing specifically about pedagogy, Lewis and Norwich (2005) call this the 'individual differences' position in which learners are considered to have needs that are common to all, and needs that are unique to them as individuals. Many of those holding this strong position on inclusive education, drawing on the social model of disability, would argue for a recognition of human diversity (including disability) as normal, and that all environments should be broadly inclusive of the diversity of learners that might be found locally. What is needed therefore is a study of the barriers to learning that children face in their school or community, such as how many schools deny entry to some local children, rather than a study of numbers of disabled children and their 'needs'.

In the second position it is argued that in addition to their educational needs that are common to all children and young people, and their unique needs, disabled learners also have needs that are specific to them as members of sub-groups, although these sub-groups are not necessarily defined by medically inspired impairment categories (Norwich, 2008). Lewis and Norwich call this the 'general differences' position. Writing about the UK educational context, Norwich (2008) argues that there appears to be limited group-specific pedagogy for some learners, including deaf learners, visually impaired learners and those identified as being on the autistic spectrum. Lewis and Norwich (2005) note however that even those who argue for a specific pedagogy for an impairment-based sub-group of disabled learners, describe how the application of this is dependent on individual characteristics of a particular child, including perhaps their membership of another sub-group. In other words, children do not fall neatly into categories, and can for example, have visual *and* hearing impairment. Any specialist pedagogy is therefore best described as a set of 'orienting concepts' (Lewis and Norwich, 2005) to point teachers in potentially useful directions when planning teaching and learning, rather than a pedagogical rulebook based on impairment or other categories. In the process of educational decision-making it is therefore important that understandings of potential group-specific needs are 'mediated through analyses of unique individual and common/general needs' (Norwich, 2008:147).

Building on the work of Lewis and Norwich (2005), and O'Brien (1998) these two positions are here represented in Fig. 1,
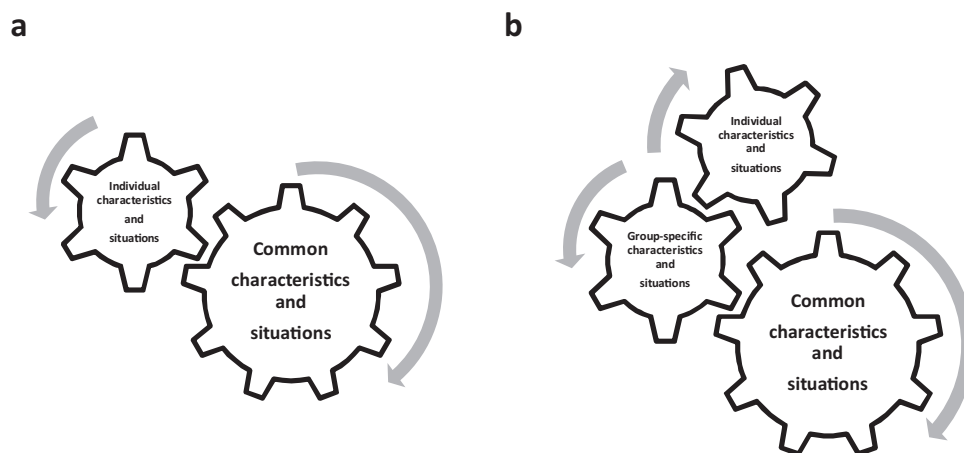
Fig. 1. Contrasting views of the characteristics and situations of children that need to be considered in inclusive educational planning and implementation. (a) Position 1 – education that responds to the needs of all will necessarily be inclusive education. (b) Position 2 – inclusive education sometimes requires specific responses to the characteristics of groups such as disabled learners.

illustrating how the common, group-specific, and individual characteristics and situations of children are seen to interrelate, and that in the process of educational decision-making it is theoretically possible to start with any of the elements or 'cogs'. Depending on one's view of disability, the cogs could represent needs located in children, barriers faced by children, or personal characteristics that interact with contextual factors to co-create disability.

These are in effect idealised positions and in practice the difference between them depends on how broadly education responds to children as children, and as individuals, in other words, the educational context. Where children's common needs are interpreted 'flexibly' (Lewis and Norwich, 2005) and individual needs are taken into account (see Fig. 1a), then Norwich argues that this can be a 'reasonable alternative' to taking account of disabled children's 'distinct group needs' (2008:145). Much of post-colonial primary education however remains influenced by the age-graded curriculum of 19th century elementary education (Little, 2006); preparing teachers to respond in large measure to learner diversity goes against the grain of schooling as currently constructed (Croft, 2006, 2010; Serpell, 1999). While it might theoretically be desirable to see all children as having individual characteristics (some longstanding and others fleeting) that affect their learning, in practice this degree of personalisation of learning is hard to achieve even in well-resourced schools in rich countries (Teacher Development Agency, n.d.). Where an education system is unable to take much account of even the common characteristics of children due to limited funds, and individualism is not traditionally valued (Croft, 2010), then group-specific responses needed to include disabled children are likely to be created or expand (Fig. 1b). Specific responses to disabled learners would be necessary because disabled children are likely to be particularly badly affected by poor quality schooling. A dearth of textbooks or poor quality chalkboards will, for example, affect all children's education, but they are likely to disproportionately impact the ability of deaf children and children with low vision to learn. Thus while there appears to be a small core of pedagogical 'orienting concepts' and other interventions that are specifically useful for planning the learning of groups of disabled children, there might additionally be other pedagogy and broader educational interventions that are 'masquerading' as specific to disabled children although ideally, if funds allowed, they would be provided for all children (Lewis and Norwich, 2005).

This paper argues that given current pedagogy and resources in many low-income countries the pragmatic 'twin-track' approach of both general quality improvements and some specific interventions will be needed to include disabled children in learning (Croft, 2010; Giffard-Lindsay, 2007; Miles and Singal, 2010). This approach has similarities to Le Fanu's (2011) 'grounded inclusionism'. While general quality improvements would significantly improve the education of many disabled children, they are either (a) unlikely to be sufficiently available in many contexts (Lang and Murangira, 2009), or (b) it would not be efficient to provide all that every disabled child might conceivably need in every class.

2.3. Planning a responsive education system

In order to analyse more systematically the reforms needed, Fig. 2 suggests a framework of the location of potential interventions to enable each level of the education system to fulfill its functions inclusively. At the school and classroom level, analysis could usefully draw on some elements of the 'Index for Inclusion' (Booth and Black-Hawkins, 2001; Engelbrecht et al., 2006; Grimes et al., 2007). Given that teacher autonomy is frequently limited, however, many significant interventions will be needed at higher levels to develop inclusive education systems

Fig. 2. Sites of possible educational interventions to support the access of disabled children and youth to schooling.

(Ainscow, 1999; Howes et al., 2011). For example, national-level reform would be needed to counter the discrimination exposed by a specialist resource teacher in Ghana who found it impossible to get large-print examination papers for visually impaired primary-school students (Yamaoka, 2011).

If specific provision of some sort is sometimes needed, then a further question is: do we need to categorise and count children to determine aspects of the educational response needed, or do some or all types of specific provision not require disability prevalence data? For some interventions we need only know that there are disabled children, for example, to design textbooks with positive images of disabled people, and to prepare teachers to have a reflective, problem-solving approach to supporting disabled learners' access to school and access to learning (Croft, 2010; Miles, 2009). A Ghanaian student teacher interviewed while on teaching practice at a school that included visually impaired students in mainstream classes described how she had been able to develop knowledge acquired at college:

> At the first term in this school, it was not easy to know their [visually-impaired students'] problems even though I learned about special needs. But I have interacted with them continuously based on what I learned in college and what other teachers teach me. [Now] I find out their difficulties and feel less difficult. (Bak, 2011:50)

Deaf learners' designated local language was previously Kiswahili in the Kenyan primary school leaving examination. Few students knew this language and so many failed the examination (Kimani, 2012). It did not require knowledge of the numbers of learners affected to change the local language to Kenyan Sign Language and thus remove this barrier to school success.[4]

There are however some potential reforms that would be informed by knowledge of the prevalence of various impairments in school-age populations. For example, providing communication support so that deaf and visually impaired learners can fully participate in school is a requirement under the CRPD. This is frequently structured through itinerant teachers who often have a dual teaching and teacher advisory role (Lynch and McCall, 2007), or through units or resource bases (Kimani, 2012; Miles et al.,

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[4] There are ongoing problems with full implementation however as the current examination attempts to assess Kenyan Sign Language in a written paper (Kimani, 2012).
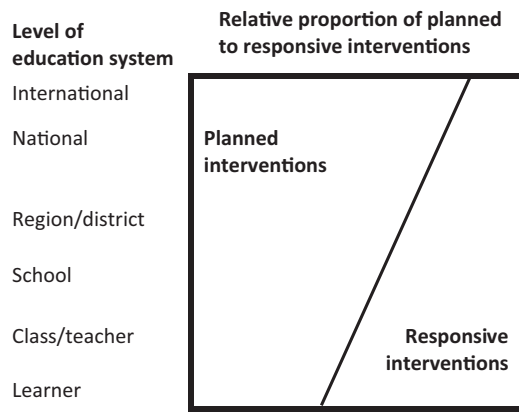
Fig. 3. Developing a responsive education system: balance between planning and response.

as school and population density, terrain, and the related ease and cost of travel. For example, the Botswanan model of providing an allowance for a teacher in each primary school to perform extra duties to support the education of children having difficulty learning (Phiriyane, 2010), appears a pragmatic way forward in a middle-income, sparsely populated country. Educational provision for disabled children is however often fragmented and less than comprehensive with perhaps two or more government ministries involved as well as considerable local, national and international NGO involvement (Alur, 2002). Therefore, although many reforms do not require disability prevalence data, in order to extend education to all disabled children, this section has argued that some information on numbers of disabled children (disaggregated in various ways) would inform the planning of a responsive national system. The following section will discuss what kind of information might be collected and factors that affect the feasibility of collecting this data in typical contexts of low and middle-income countries.

2011). Imaginative out-of-school support is also being developed, such as after-school and holiday clubs for disabled learners among others (e.g. Anand, 2009). Knowing the approximate demand for such services would help with intervention design. As with emergency education (INEE, 2010) there must be adequate planning so that a timely response can be made to educational barriers as they are faced by disabled children. It is argued here however, that as we move down the education system, there will be less certainty about exactly what is needed where in order to extend education for disabled children (see Fig. 3). National systems therefore need to be designed to give flexible support to disabled children's participation in education at local levels.

The balance between planning and response will alter depending on context, and the slope of the line might be steeper or shallower or curvilinear. For example, it could be expected that when an impairment is highly prevalent, such as when children experience general or specific difficulties with learning, then more could be planned as this would be expected in every class (see Fig. 4a). Conversely, when an impairment is less prevalent in a particular context, then at the local level a more responsive system is needed, with most of the planning being at regional level and above (see Fig. 4b). For example, as the prevalence of learners needing to use Braille is generally low, a Braille textbook supply system needs to be planned at regional or national level so that it can be drawn on as need arises by schools.

The structures developed to date to support access to education for disabled children in low and middle-income countries are likely to have been influenced by funding and geographical factors such

3. Obtaining childhood disability prevalence data

Collecting and analysing data on disability prevalence in general (Fujiura et al., 2005) and more specifically on disability prevalence among children and young people is conceptually complicated with related logistical and ethical difficulties (Robson and Evans, 2003).

3.1. Defining disability

As has been seen in Section 2.2 above, definitions of disability are dynamic and contested. Metts explains the issue:

> Disability is a normal phenomenon... it should be possible to estimate the sizes of the various disability populations, determine their needs and develop appropriate and cost-effective strategies to meet those needs. This is yet to be accomplished however, largely because disability is a complex interconnected bio-medical, social and environmental phenomenon that is yet to be fully analyzed and understood (2004:2).

As a result, while some surveys and censuses based implicitly on a medical model of disability equate disability with impairment and therefore seek to count rates of impairment, others look at the impact of impairment, i.e. restricted activity and unequal participation. Impairment-based surveys of disability generally find lower prevalence rates than surveys of activity limitations
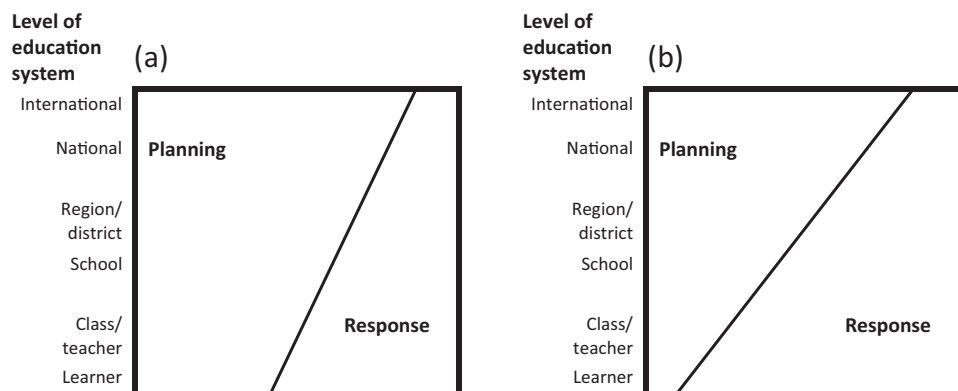

Fig. 4. Developing a responsive education system: relative proportions of planned to responsive interventions. (a) High-prevalence impairment. (b) Low-prevalence impairment.

(Mont, 2007). Fujiura et al. (2005) explain that this is because questions about impairment are affected by unfamiliarity with terminology used and the stigma associated with disability which can lead to underreporting.

The most comprehensive effort to measure disability from an interactionist perspective is the World Health Organisation's International classification of Functioning, Disability and Health (ICF) introduced in 2001 and the subsequent ICF-CY, an adapted version applicable to children and young people (WHO, n.d.). Here the emphasis is shifted from a medical diagnosis to 'functioning'. Disability is seen as a 'decrement in health', thus attempting to 'mainstream' disability as something everyone can experience to a degree. The social nature of disability is acknowledged by measuring an individual's participation in society and the impact of contextual factors on their functioning (WHO, 2002).

In a somewhat similar vein the Washington City Group on Disability Measurement (a United Nations Statistical Division collaboration between national statistics agencies) noted that 'Disability as an umbrella term refers to problems, such as impairment, activity limitation or participation restrictions that indicate the negative aspects of functioning.'[5] Although in this definition the attempt to 'mainstream' disability is not found, disability is about 'problems', and also disability as something experienced is exchanged for 'an umbrella term'. The three-way analysis of disability as impairment, activity or functional limitation and restricted participation is also found in a UNICEF/University of Wisconsin (2008) report on the use of household survey data to monitor childhood disability in developing countries, where it is noted that:

> Such definitions emphasize that restricted participation in society might result not only from impairments or functional limitations, but also from contextual factors such as: buildings and transportation that are not accessible to persons with mobility limitations; social stigma; or policies, written and unwritten, that exclude children with disabilities from schools or other settings. (2008:6)

The same report also however gives a definition that focuses much more on impairments:

> Child disabilities, or developmental disabilities, are limitations in mental, social, and/or physical function relative to age-specific norms (2008:7)

Here the focus is very clearly on deviation from a norm and the reference to age-related development highlights the additional complexity of measuring disability among children (Ruyobya and Schneider, 2009; Stobert, 2009). It is often hard for all involved to tell whether a young child is temporarily delayed in their development in a particular area or whether they will have a long-term potentially educationally significant impairment. Parents can also experience the emotional tension of wanting to get help for their child while fearing the consequences of voicing their concerns. Albert et al. note that despite the ICF there are still 'major disagreements about precisely what is being measured' (2005:27) while Eide and Loeb (2005) argue that it is difficult to decouple studies of disability prevalence from an impairment-based approach to disability. The ICF is a complex somewhat 'cumbersome' system that nevertheless usefully conceptualises disability (Metts, 2004), although much work would be needed to select relevant items from it for education surveys (Hollenweger, 2008).

3.2. Differences between disabled children

Recent developments in disability theory have emphasised diversity within disabled people's experience (as discussed in Section 2.2). For educational interventions, the level of impairment can make a difference. For example, children with severe or profound pre-lingual deafness are likely to need sign language to progress with their education, whereas children with more moderate hearing impairment acquired later will be less likely to need this. Mont (2007) suggests collecting disability prevalence data at two levels of impairment given the different interventions that levels of impairment often imply. Similarly, four levels of response to the Washington City Group's short set of questions were recorded in the Tanzanian disability survey (Ruyobya and Schneider, 2009).

The estimates of very different prevalence for moderate compared to severe impairment quoted in Section 1 (WHO/ World Bank, 2011) also suggest that the scale as well as the type of interventions needed by these two groups will be different. From experience of implementing inclusive education in India, Mani (1995 cited in Bangert, 1996) argues that around 75% of disabled children could access education in mainstream classes with a little additional support, such as a two-week professional development course for teachers. This chimes with the author's experience as a regional advisor on inclusive education in Namibia where relatively few children with severe educationally-significant impairments were found in a 3-year concerted effort to find all disabled children in- and out-of-school by staff from several ministries and the local Leonard Cheshire community-based rehabilitation (CBR) programme. Many disabled children identified had moderate impairments for which relatively low or no-cost interventions could increase their access to learning (Croft, 2010). This key point is sometimes missed in arguments against inclusive education in low-income countries. Within the population of disabled children there are therefore likely to be those who are much easier to assist to access education than others, suggesting parallels with work on the 'easy-to-assist' and the 'hard-core poor' (Hulme and Shepherd, 2003; Matin and Hulme, 2003 cited in Rose and Dyer, 2008).

Acknowledging different levels of impairment implies a view of disability as a relative condition albeit much simplified for the purposes of data collection and analysis. Disability can therefore be seen as a quality defining a discrete group of people, or as a relative condition. Eide and Loeb (2005) consider that these two contrasting strategies for developing disability statistics both have their merits, but they warn that:

> It is however of importance to distinguish between the two and to be explicit about the basis for collecting disability statistics both with respect to analytical and "end-point" requirements. Failure of distinguishing between the two strategies may lead to… confusion in the conceptual basis for disability statistics, leading in turn to problems with respect to comparability, representation and application (Eide & Loeb, 2005:20)

Seeing disabled children and young people as one discrete group can be useful for highlighting inequality in educational access, but is of less use for planning and implementing reforms to address this.

3.3. Ethics and costs

Given the extremely challenging circumstances of many families with disabled children, there are serious questions

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[5] http://www.cdc.gov/nchs/about/otheract/citygroup/rationale.htm (accessed 7.7.09).

about the ethics of disability-specific surveys without an accompanying service as these can raise expectations of provision (Lewis, 2009; Robson and Evans, 2003). Furthermore, surveys can be of disproportionate cost (de Beco et al., 2009) and take considerable time to administer and process and thus inclusion can be delayed (Robson and Evans, 2003). Yeo and Moore (2003) argue that surveys should not be carried out as an alternative to provision. Robson and Evans (2003) therefore argue that disability should be surveyed only within a national census or more general household survey. In terms of survey design, there are clear advantages to having a disability module as part of a broader study, both logistically, and to allow for large-scale analysis of links between impairment, educational participation, and other factors that put children and youth at risk of educational marginalisation.

The following section gives two examples of efforts to generate childhood disability data as part of more general household surveys. Household surveys potentially identify the large numbers of disabled children who are thought to be out-of-school in low and middle-income countries, where the school-based surveys of students common in higher-income countries are of limited use (Gottlieb et al., 2009).

3.4. Disability in UNICEF's Multiple Indicator Cluster Survey (MICS)

The optional disability module of the MICS is explicitly aligned with the ICF interactionist view of disability. The stated aim is to use 'collected data to explore associations between existing impairments in children's activities and participation in life situations, and their contextual factors.'[6] The 'ten question screen' used in the disability module has the advantage of having been designed for contexts where few disabled children have previously been identified. It performed well as a first-stage screen to identify children with 'serious cognitive, motor and seizure disabilities' for subsequent further investigation and support, but was not found useful for children with hearing or visual impairment (Durkin et al., 1994). It was recommended by Robson and Evans (2003) to address their concerns with existing data sets. The ten-question screen uses apparently simple terminology, and focuses on 'observable behaviours' (Hollenweger, 2008) including some activities common in daily life. A positive result, that is where a main carer answers 'yes' to a question such as 'Compared to other children does (name) have difficulty seeing, either in the daytime or at night?'[7] is considered to indicate a child at increased risk of disability.

Gottlieb et al. (2009) analysed data from 18 countries in the third round of the MICS, 2005–2006, in which nearly twenty thousand children were screened. They found that, 'Children aged 6–9 years who did not attend school screened positive for disability more often than did children attending school (29% [2–83] vs 22% [3–47]) in eight of 18 countries' (2009:1831). This difference was however only significant in seven of the 18 countries.

Hollenweger (citing Grieger and Martinho, 2006) raised concerns about the performance of the disability module in the MICS particularly in relation to younger children, with some countries reporting that the prevalence of 'developmental delays and other problems for children under the age of three was as high at 100% (mainly owing to the talking item)'(2008:21). Differences between age groups and countries were also found to be extreme

'ranging from 0% in Sierra Leone, and 20% in Iran to more than 80% in Cameroon, and almost 100% in Madagascar' (Hollenweger, 2008; see also Loaiza and Cappa, 2005). She attributes these results to the fact that the MICS is administered in:

> ...diverse cultural settings where little formal knowledge of categorization systems or disability can be assumed. The information collected is therefore not embedded in a clinical practice or tradition and responses may be dependent on situational factors (training of interviewer, social acceptability of response, developmental stage of child). (Hollenweger, 2008:22)

Attempts were made to make the second round of MICS more robust by having a second stage medical and psychological assessment for all children who screened positive and a random sample of 10 percent of those screening negative. However, this did not take place in any of the countries using the optional disability module 'mainly due to lack of planning, as well as for logistic reasons and budget limitations'[8] and so was later abandoned. Further limitations of the MICS are that it is not linked to educational factors (Hollenweger, 2008) and that its cross-sectional design means that it is difficult to make inferences about causality or direction of effects (Gottlieb et al., 2009).

3.5. Disability in the CREATE longitudinal study of school drop-out in Bangladesh

Sabates et al. (2010) report on a household study of over nine thousand children aged 4–15 years in poor areas of Bangladesh. As a longitudinal study it addresses Gottlieb et al's criticism of the MICS. In asking 'Is x [child's name] disabled?' the survey used a broad question which would probably interpreted as impairment-related. Responses of 'Yes' or 'No' were provided by the main carer thus counting disabled children as one discrete group. In the analysis children were counted as disabled if a positive response was recorded in 2007 or 2009 as an ongoing condition was assumed that might not have been recognised or declared on one or other occasion. A further activity-based question ('Does x normally play like other children?') could perhaps function as a proxy indicator for disability, and for this the main carer could choose between four levels of response. In the analysis three of these responses were taken to indicate that the child does not play 'normally'. The main carer's report of a child's health status could also potentially overlap with disability.

This study found a disability prevalence rate of 2.6% (n = 163). The longitudinal nature of the study also allowed comparison between various groups regarding enrolment and 'drop-out' over time. As shown in Table 1, a child not in school in either 2007 or 2009 was more likely to have been identified as disabled, to be reported as having bad health or described as not playing 'normally' compared to children who were continuously enrolled over the period. Children who 'dropped out' were less likely than those permanently excluded to be identified as disabled, but more likely to be described by their main carer as disabled than those who remained continuously enrolled.

This study had the advantage of exploring educational access for disabled children within broader research and thereby avoided the ethical issues associated with conducting a disability-specific survey. The study design also provides the potential to explore intersectionality by investigating

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[6] UNICEF Childinfo, Statistics by area, Child Protection, Defining Disability http://www.childinfo.org/disability.html (accessed 7.1.12).

[7] UNICEF MICS 3rd Round optional childhood disability module http://www.childinfo.org/files/MICS3_Child_Disablity_Module_English.pdf.

[8] UNICEF Childinfo, Statistics by area, Child Protection, Methodology http://www.childinfo.org/disability_methodology.html (accessed 7.1.12).

Table 1
Child characteristics and school-enrolment status, CREATE household survey, Bangladesh.

	Permanently excluded (out of school in 2007 and 2009)	Drop-outs (in school in 2007 but not in 2009)	Continuously enrolled (in school 2007 and 2009)
Described as 'disabled'	14%	4%	2%
Described as having 'bad health'	23%	13%	13%
Described as not playing 'normally'	18%	6%	4%

Source: Tables 3 and 10 from Sabates et ?al. (2010).

relationships between disability and other factors affecting access such as poverty, ethnicity, gender, household attitudes to learning and support for homework, enrolment, school attendance, and 'drop out'. Disabled children can be compared with non-disabled peers, and data on disabled children can also be disaggregated by various background characteristics. Further CREATE (Consortium for Research on Educational Access, Transitions and Equity) research also studied local schools. Risk factors for never being enrolled in school and for leaving school early can be explored. In short, the study sees children within the context of their household and school.

Disadvantages of the study design stem largely from the single specific question addressing disability. A lack of disaggregation by level and type of impairment means that the prevalence data are of limited use for planning and implementation of inclusive educational provision although they can highlight unequal access. Space in the survey was limited due to the range of factors being studied, and there was therefore no space for questions relating to activities, participation and barriers originally drafted (see appendix). Although CREATE surveyed 6606 households, given current indications of relatively low childhood disability prevalence rates, a larger sample might be needed to give a clear picture of prevalence, particularly if information disaggregated by level and type of impairment is required.

4. An alternative way forward

Including disability in more general household surveys and censuses addresses some of the ethical concerns with disability surveys, but problems with defining disability and training enumerators are likely to be exacerbated. The various limitations of surveys of childhood disability prevalence discussed so far do not suggest however that attempts to inform the extension of education for disabled children with reliable data should be abandoned. An alternative to a national survey of disability prevalence followed by planning and implementation, is to start at the lower levels of education systems with implementation, and from this to learn lessons from local interventions to inform broader analysis of national needs so that education can play a positive role in breaking the link between disability and poverty.

There are several advantages to this 'bottom-up' approach. Service-based research can ethically generate quantitative data (Robson and Evans, 2003). It will also draw on developing understandings of what is likely to constitute educationally significant impairment in a particular context, and of the kind of information that is needed to improve education for disabled children. Where disabled learners are in education, the barriers to their access are increasingly exposed to teachers, parents, and learners themselves. For some families, recognising a child's impairment, or even publicising the existence of a disabled child, might cause considerable stigma. Provision of a service, or disability allowance, might swing the balance of risks involved

(perhaps weighed subconsciously), in favour of declaring the existence of disability. Where interventions include identifying local disabled children as part of their work (Choudhuri et al., 2005) they are therefore likely to find a greater proportion of disabled children than surveying without a service. Information can also be collated from disabled people and their organisations, and other key informants working in community-based rehabilitation, health and other services (Muhit et al., 2007). Eide and Loeb (2005) argue that the involvement of disabled people's organisations throughout research is important for the strength and credibility of findings and recommendations.

Although data can be generated and used locally, as in community-based education management information systems (C-EMIS) they can also be used to inform higher levels of the education system (Heijnen, 2004). Where services have identified the demand for support to access education, such as that needed by deaf children, this knowledge can be extrapolated to predict likely demand in other similar areas (Miles et al., 2011). Trial initiatives can also test demand. For example, general advisory teachers for disabled children might reveal demand for sensory impairment-specific support teachers. The scaling up of initiatives in educational provision is recommended in the recent World Disability Report (WHO/World Bank, 2011).

Alongside the development of quantitative research, there is a role for qualitative studies although these are sometimes undervalued and underfunded (Robson and Evans, 2003). Smaller scale qualitative research can build up understanding of the interactions that construct and deconstruct disability in context (Jeffery and Singal, 2008) including the perspectives of children and young people (Robson and Evans, 2003). A secondary school student with visual impairment quoted in Yamaoka's recent study in Ghana provides an example:

'When the teachers write on the board, they ask me if I can see it. I can see the board, but sometimes teachers' handwriting is weak, and sometimes they write small. But when I complain to teachers, they start writing big.' (2011:31)

Exploratory work of this kind can also inform the development of quantitative measures, including measures of empowerment and voice (Hughes and Hutchings, 2011).

5. Conclusions

The central question addressed in this paper is whether a survey of childhood disability prevalence is a necessary and feasible place to start when extending education for disabled children in low- and middle-income countries, who are at risk of becoming or remaining poor without it. Mostly, what disabled children need in order to succeed in school, as with other children, is a good-quality responsive education. For some potential disability-specific reforms it would however be useful

to know the likely numbers of children with educationally significant impairment in order to plan aspects of a responsive education system. As long ago as 1993, Coleridge warned that overestimating disability prevalence could be as dangerous as underestimating it; over-estimates can imply that promoting the equality of disabled people is an almost impossible task and could thus discourage governments with limited budgets. Levels of impairment and likely educational consequences are significant here. It is unlikely that most disabled children have complex and potentially very costly specific educational requirements. Many children have moderate impairments that, where a specific response is needed, can be addressed with comparatively modest costs to education. There is however a degree of unpredictability to the type and location of interventions that will be needed, and so inclusive systems need local flexibility.

Balancing on the one hand the potential usefulness of some data on school-age disability prevalence disaggregated by various factors, and on the other hand the logistical and ethical difficulties and costs of obtaining such data, this paper argues that in many contexts a national survey of childhood disability prevalence would not be the most useful starting point for extending education for disabled children and young people. For planning and implementation, overall numbers of disabled children are of limited use. Breaking down school-age populations of disabled children, however, into more potentially useful categories faces the increased costs and complexities of defining levels and types of impairment, activity limitations and participation, and consistently operationalising such definitions in the large-scale surveys that would be required to generate statistically significant data. In the light of the many difficulties with childhood disability surveys there is a clear rationale for collating information on the numbers of disabled children from existing sources. Figures from support programmes are likely to be more accurate than survey-based methods as the provision of a service shifts the balance in favour of declaring disability. Working together to include children in education also helps develop a shared recognition of what constitutes educationally significant impairment, and how disability is constructed, in a particular context. As provision increases, disaggregated figures on participation in education will help identify specific barriers to access, but action should not wait for data. Rather, making the most of service-generated knowledge is the most cost-effective and pragmatic way to extend education for disabled children.

Finally, returning to Stubbs and Lewis' comment that the inclusive education debate needs to focus on 'power, participation and achievement in learning' (2008:46), the degree to which disabled children and young people are able to contribute their knowledge as experts on their own lives is important. As well as considering the views of disabled people's organisations more broadly, a responsive education system would draw on the knowledge of individual learners about what helps and hinders their learning. Rose and Dyer (2008) argue that voice and agency are important outcomes of education to enable marginalised people to make use of education to break out of poverty; the situation of disabled learners demonstrates the potential of a responsive education system to enable voice and agency to be a means as well as an end of educating some of the poorest children and young people.

Acknowledgements

Appendix A

Items on disability drafted by author for CREATE household survey, 2007.

ID code	Name	Can** see, hear, walk and talk as well as other children his/her age? Y/N If Yes go to Q40 If No go to Q39	What does** find difficult? (Record code for all that apply) Seeing = S Hearing = H Talking = T Walking = W	Can** understand instructions, take part in household chores, and look after his/her personal needs (prompt: washing, toilet, dressing, feeding) in the same way as other children of his/her age? If Y go to Q? [next section] If N, go to Q41	Is it more difficult for** to make the journey to school than for other children in the family? 1 – cannot make the journey to school 2 – needs extra time/help 3 – no effect	Have there been any problems registering** in a school because of these difficulties? 1 – school not willing to register** 2 – difficult to register** 3 – no problem 4 – registered at special school/class	Have***'s difficulties affected their progress at school? 1 – a lot (e.g. dropped out, repeating grades) 2 – moderate amount, child is struggling to keep up with schoolwork 3 – no effect–child doing well at school	Have the teachers made an effort to find ways of including** in school activities? 1 – a lot, they have got specialist advice, made changes to school buildings and routines 2 – moderate amount, e.g. they give some extra help after class 3 – not at all
36	37	38	39	40	41	42	43	44

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