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Illiteracy among Adults with Disabilities in the Developing World: An Unexplored Area of Concern

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Abstract

In the early 1990s, UNESCO estimated that perhaps 97% of the world's 650 million disabled persons were unable to read or write, leading to significant efforts throughout the developing world to ensure that all children with disabilities attended school through 'inclusive education' programs. But what of the vast majority of persons with disabilities who now are adolescents or adults, well beyond the reach of classroom education, or the estimated 90% of disabled children who will 'age out' of the system before such inclusive education is available in their communities. In this paper, we review findings from a global literature search on literacy of adults with disability in developing countries which shows that there is currently little in international development, education, health, or disability studies that addresses this issue. On the basis of these findings we argue that while inclusive education efforts for children are important, more attention also needs to be directed to providing literacy skills to illiterate and marginally literate disabled adolescents and adults. A concerted effort to improve access to basic literacy and numeracy skills through both inclusion in general adult literacy programs and disability specific adult literacy programs is urgently needed to reach the goals for education and poverty eradication established by the new United Nations Convention on the Rights of Persons with Disabilities and by the Millennium Development Goals.

Introduction

While the 650 million people worldwide who live with a physical, sensory (blindness, deafness), intellectual or mental health disability make up 10% of the world's population, according to the World Bank, they make up 20% - or one out of every five - of the world's poor. (Elwan: 1999) In the early 1990s, UNESCO estimated that perhaps 97% of these people had either never seen the inside of a classroom or had left school too early to have mastered basic literacy and numeracy skills resulting in literacy rates for adults with disabilities in developing countries possibly as low as 3% overall, and for women with disabilities, 1%. (Helander: 1993)

These statistics became an area of significant concern and helped lead to the 1994 Salamanca Statement and Framework for Action on Special Needs Education. The Salamanca Statement, building on the right to education for all guaranteed in the UN Convention on the Rights of the Child, stated: "(we) hereby reaffirm our commitment to Education for All, recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs..." (UNESCO, 1994).

The right to education is strongly supported in the newly ratified Convention on the Rights of Persons with Disabilities (UN, 2006) where Article 24 states that "States Parties shall ensure an inclusive education system at all levels and lifelong learning ... "Although the right to education is primarily framed as a school-based issue for children, certain articles of the Convention are linked to adult literacy. Article 24 itself refers to 'youth and adults', and Article 21 re-affirms the freedom of expression, opinion, and access to information, while Article 29 refers to the right to participation in political and public life. (UN Declaration 2006) The ability to exercise these rights is directly related to the mastery of literacy skills.

The right to and need for education for all disabled children worldwide has led to the Inclusive Education movement, crystallized by the Salamanca Statement. Over the past fifteen years, significant progress in both legislation and programming at local, national and international levels has increased school attendance by disabled children throughout the developing world. (UNESCO website) In many countries, growing numbers of teachers and educators are receiving training in how to include disabled children in general classrooms while many others are receiving specialized training in teaching blind or deaf children, those with intellectual disabilities or children with behavioral problems. While there is an on-going debate about whether children with certain types of disabilities learn best in specialized schools, or are better served in general classrooms, there is strong consensus that all children with disabilities can learn and are entitled to an education. (Inclusion International 2009)

However, inclusive education efforts and specialized schools only provide services to children and adolescents who are already or are soon to be, in school. Furthermore, even with significant increases in current inclusive education programs and in services provided by disability-specific schools, millions of children will still not be reached by any educational program before they reach adulthood. (UNESCO website 2009)

What of the vast majority of persons with disabilities who are adolescents or adults, now beyond the reach of classroom education?

Given the competing demands of making a living, raising families and fulfilling other adult responsibilities, school-based education for them, at this point, is unrealistic. They live – and will continue to live for decades to come – unable to read or write, and without access to at least basic literacy skills, breaking the links between poverty and disability will be extremely difficult, if not impossible. Empowerment, advocacy and meaningful engagement in civic and political life will likewise be limited if they remain illiterate. In the following paper we discuss the reasons why so many persons with disabilities arrive at adulthood illiterate, and review the data currently available on literacy among disabled adults in the developing world. We then discuss links between literacy, poverty alleviation and disability, before ending with recommendations for future research and action.

Background

While inclusive education along with continuing educational opportunities offered by specialized schools and targeted programs is beginning to make inroads into the number of disabled children attending school, until only a few years ago few persons with disability received any formal education. For example, according to the UN, in the Philippines in 1990, only 1.16% of the nation's 3.5 million school aged children were disabled, in Ethiopia only 1%, and in Mozambique, only 0.7%. (UN 1990) A disabled child from any of these countries who was 5 years old in 1990 would be 25 today, and given the limited availability of education for older disabled children, adolescents and adults, it is highly unlikely that existing educational deficits would have been made up in the intervening years.

There are several well-established reasons why adults with disabilities were, and still are far less likely than non-disabled peers, to have attained at least minimal literacy skills. Barriers to education in childhood include the fact that until quite recently, in many countries, when a child was born with an identifiable disability, it was assumed education was not needed as they would not live to adulthood. (UNICEF 1999). Even if it was anticipated that a child would live beyond the first few years, in many cultures, it has long been believed that such a child could not learn or could learn only with difficulty – something we now know is incorrect for the vast majority of disabled children.(UNESCO 2005) Another frequent barrier has been the assumption that a disabled child does not need an education because the lifelong responsibility of supporting such a person lies with the family– something that is not only often not the case, but also limits the right of adults with disability to decide for themselves where, how and with whom they live. Compounding this, in many societies, it has been assumed that a disabled child could only do the most menial jobs, and therefore education was unnecessary. Furthermore, in countries with school fees and uniforms, poor parents often choose to educate their non-disabled children assuming that these children would provide for their disabled sibling after the parents reach old age or die.

All these assumptions and impediments have led many families to keep their disabled child home to do routine chores. (UNICEF 1999)

Within schools, similar beliefs among staff and teachers constitute another set of barriers to education. School officials, even if committed to educating disabled children, often are unaware of where these children live. Parents are sometimes slow to get birth certificates for children born with significant disabilities, when registering a child requires a trip to a distant village centre or a fee, especially if it is assumed that the child will not live long enough to justify the effort or expense. (Groce 2006; Thorburn 1999) Stigma, particularly in societies where the birth of such a child is taken as evidence of parental sin or misconduct, makes family members reluctant to admit there is a disabled child in the household should school officials or census takers come to the door. Lacking birth certificates or census data, school officials may not know of the child's presence or needs. (Groce 2006)

Even if all these barriers can be overcome, actually getting into a classroom continues to be difficult for millions of disabled children. Children with mobility impairments often cannot physically walk to school or up stairways into a classroom, deaf or blind children find that without sign language interpretation, large print or Braille, they cannot follow lessons, children with intellectual disabilities are often unable to keep up in classes if no allowance is made for their special learning needs or if education is focused on passing standardized national exams that have little relevance to their educational needs. Even if a disabled child can get into the classroom and cope with school work, it is not unusual for them to arbitrarily be sent home by teachers or principals who believed them a distraction to other children, or who receive complaints from parents of non-disabled classmates fearing such children slow the pace of education for others.

Inclusion of disabled children into general classrooms versus specialized disability-specific schools is a hotly debated topic. (World Blind Union 2002, World Federation of the Deaf 2004) As we are focusing on adult literacy rather than school-based education, we will not discuss the various arguments for and against inclusion here. However, we do note that currently inclusive education efforts while expanding, by many estimates are still not reaching 90% of all disabled children in developing countries, with a disproportionate number of the unreached children being in rural areas and poor urban and peri-urban neighborhoods. (Peters 2003; World Bank 2003) At the same time, while some countries have had specialized schools for many years, these schools are invariably limited in the number of children they can take. In most developing countries, specialized systems currently accommodate no more than a few hundred to a few thousand children nationwide, thus effectively having waiting lists of thousands if not hundreds of thousands of children. (Inclusion International 2009) Furthermore, it is estimated that only 5% of all disabled children who do enroll in school complete their primary education with many leaving after only a few months or years, and often leaving because they are gaining little from the experience.

(UNICEF 1999; Peters 2003) Such children will join the ranks of illiterate or marginally literate disabled adults.

Thus, the vast majority of persons with disabilities arrive at adulthood without having mastered basic literacy or numeracy skills. The question then becomes what efforts are in place to enable these millions of disabled persons to make up such deficits once past school age?

Adults with Disability: Review of Existing Information

As researchers in international development, we have long been struck by the relatively small amount of attention given to illiteracy among disabled adults – an issue we routinely encounter in the field. Given all we know about the limited resources for educational opportunities for disabled children, the lack of attention to literacy among adults with disabilities is perhaps not surprising. However, in order to ascertain what is actually known, we undertook a comprehensive literature search on literacy among disabled adults in the fields of education, international development and global health, as well as searches using such cross-cutting themes as disability and literacy.

We concentrated specifically on locating information from three complementary data sources:

- Academic journals,
- UN and bilateral governmental websites and documents, and
- Resources compiled by non-government organization and field initiatives.

To supplement the limited amount of materials we located in these fields, a series of informal, semi-structured interviews with 30 key policy makers in international development and international disability fields (15 in each field) were carried out in 2008-2009, in an attempt to identify policies or programs that may be underway but have not yet entered the peer-reviewed or grey literatures.

We applied a comprehensive grid for analysis, focusing on identifying:

- 1) any available statistics on literacy or illiteracy rates among disabled adults;
- 2) locating and reviewing papers and reports that address theory, policy or practice in either disability-specific or general literacy programs targeted at disabled adults in developing countries;
- 3) information or descriptions of literacy programs for adults that were disability-inclusive or that specifically encouraged adults with disabilities to take advantage of services offered to general populations;
- 4) publications that linked illiteracy among disabled adults to poverty, unemployment or empowerment issues.

The first phase of the search reviewed academic research through the following general databases: Google scholar, ERIC, JSTOR, ISI Web Of Science, SCOPUS and

MedSci, using the key words 'disability', 'adult', 'literacy' and 'illiteracy'. Journals that particularly focus on one of the central themes of our search: literacy, adult education, disability and development were next searched using keywords but also concepts related to our queries: inclusive education, functional literacy and special education in combination with our key concepts.

Due to the interdisciplinary nature of the subject, the variety of groups and subgroups involved within the disability community itself, and the number of different professional fields, associations and societies that may be addressing this issue, in a second phase we focused on a range of secondary data sources, such as UN agencies, professional organizations, advocacy and interest groups that specialize in disability and/or education in developing countries. The intention was to identify policy documents, committee reports, white papers, campaigns, and calls for action or any other materials that might indicate attention to this issue. Websites were searched for resources that refer directly to literacy of disabled adults using related concepts such as inclusive education, adult education and special education, as well as illiteracy, literacy and functional literacy. This was done with the intention of identifying material relevant to adult literacy for persons with disability even when not directly addressed in the document.

A full listing of all sources is listed in Appendix A. To summarize our review, over the course of two months we reviewed 26 prominent journals in education, special or inclusive education, adult education and education in international development, 14 UN websites, including all the prominent organizations involved with disability and development issues and 19 websites run by leading DPOs and NGOs. Additionally, 14 major reports were reviewed by UNESCO and other organizations that sought to summarize global literacy issues, as well as 26 articles located in the literature through ISI Web of Science or JSTOR that specially addressed literacy, education or learning and disability or inclusive education in their titles.

Policy makers were asked : 1) had they themselves experienced working on literacy or illiteracy issues among disabled adults as a distinct area of concern and 2) did they know of any programs, policies or outreach efforts intended to provide literacy skills to previously illiterate or marginally literate disabled adults. Experts working in disability were asked if they or any of their colleagues been in contact with colleagues or organizations working on general adult literacy efforts; experts from international development circles were asked if they had been in direct or indirect contact with anyone working in the disability arena. Notes were kept on the response and analyzed using theme content analysis.

Findings

Our most striking finding was the extremely limited number of papers, reports or references on the subject in the literature. We were able to locate fewer than a dozen studies which specifically addressed the literacy needs of disabled adolescents or

adults who had not previously been in school, and only a slightly larger body of work (16 reports or papers) that made general reference to the situation of illiterate disabled adults in the developing world or called for action but which lacked specificity.

Literacy among disabled adults seems to be an issue that falls between the fields of disability, education and international development. When literacy and disability was the topic of academic papers, broad policy statements or websites that addressed disability and literacy, almost invariably after citing the great literacy needs among disabled people, the writers or websites immediately turn into a discussion of children and schools, with particular attention to ‘inclusive education.’ (See for example: UNESCO 2002; WHO website) While the growing body of literature on inclusive education is a welcome sign of progress, the lack of attention to adults – (or disabled children who are not currently in school for that matter) – is striking.

A small body of papers focuses on adult literacy from a theoretical perspective. For example, Clark (2006) looks at the linkages between adult literacy and disability studies. Filmer (2008) as well as Jonsson and Wiman (2001) note the economic consequences which reach into adulthood when disabled children are denied an education. There are also calls for literacy programs for specific groups or subgroups within the disabled populations. (See for example, Russo 2004), or statements of purpose for campaigns that have been planned but have often stalled, such as the UNESCO ‘Flagship on Education for All’ campaign, launched after the Dakar Conference, one of whose focal points was intended to be disability. (UNESCO 2002)

There are very few attempts to estimate the actual literacy or illiteracy rates – either among the general populations or by disability-specific groups, beyond childhood. What statistics are available, are widely divergent. The most commonly quoted figure is UNESCO’s figure estimating a global literacy rate of 3% worldwide, and for women with disabilities, only 1% (Helander 1993, UNESCO 2008). If the 3% estimate is true, of the 650 million persons with disabilities worldwide (UN ENABLE), only some 19.5 million worldwide are literate. How these figures were initially arrived at however, is unclear.

In India, the Education for All campaign is beginning to collect and track statistics on literacy rates among disabled adults. Results indicate a higher rate of literacy versus illiteracy for disabled adults than in many other countries, with basic literacy skills reported at 40%. (Education for All India 2009). However, there is also the recent report on Participation and Commitment to Outcomes by the World Bank, where adult literacy rates for people with mild to moderate disabilities are reported at 50%, and those with significant disabilities at 25% in several Indian states. (World Bank 2007)

A second group of papers found were case studies describing local initiatives to provide literacy skills to disabled adults. As a group, these tend to be small programs,

often poorly funded and not linking into larger or more sustained efforts either within the disability community or with adult literacy efforts. However, several of these papers offer intriguing insights into the potential that even basic literacy efforts can provide. For example, Indabawa (2002) describing a program in Kano State, Nigeria, reported that despite limited funding and instructors who knew little about disability, of the 380 disabled adults reached, 84.4% of these newly literate students passed a qualifying exam, enabling 70 of them to find civil service jobs. Moreover, 55.5% continued their education into post-literacy programs before the effort was discontinued because of lack of funding.

Additionally, several recent initiatives at providing literacy outreach to specific disabled populations were also identified. For example, in 2008, the government of South Africa launched the Kha ri gude campaign to foster literacy for 4.7 illiterate South Africans, focusing on illiterate adults from groups that have traditionally not been reached well by standard education. Among the targeted groups, disabled citizens have specifically been identified, with 60 sign language teachers included in the initial group of educators, the development of Brailled materials and further plans for outreach efforts to accommodate adults with a range of disabilities. (Kha ri gude 2009) These larger scale initiatives are promising in themselves and show that literacy initiatives for disabled adults can be incorporated into large scale literacy campaigns. The results of these efforts should be followed closely by the global disability community.

Additionally, there is a small body of references to building literacy skills for disabled adults within the Community Based Rehabilitation (CBR) and microfinance literatures. The CBR literature routinely calls for education, but there are strikingly few references to disabled adults. In descriptions of programs, in handbooks and guidelines as well as on websites and in conference reports, discussions about education and literacy quickly jump from broad discussions about education to specific discussions about children and classrooms. (See for example WHO; UNESCO websites) We are confident that literacy training is an important component in many CBR programs, included as one of a number of interventions intended to make participants more empowered and more economically self-sufficient. However we were unable to locate information on what percentage of CBR programs include adult literacy programs nor to identify efforts to systematically evaluate or compare literacy education efforts among different CBR programs. In other words, consistent attention to literacy among adults as a distinct area of concern within CBR remains lacking. Moreover, even where adult literacy programs are routinely included in CBR efforts, the overall impact currently will remain limited. While CBR has great potential, WHO estimates that CBR still only reaches some 2% of all persons with disability and not all CBR programs currently offer adult literacy instruction within this larger 2%. (WHO website 2009)

Likewise, a growing number of DPOs and NGOs, as well as many CBR programs, now are working on micro-credit efforts and other income generation schemes. Some

of these programs have components to improve the literacy and numeracy skills of their members but no overarching body of information or statistics could be located in our review. Few literacy programs could be identified and as with the CBR programs almost all that were identified were located by word of mouth and had not been documented in the literature or evaluated on site. We therefore strongly suspect more of these programs include adult literacy than can be currently located in a literature review such as this. However, both in CBR programs and micro-credit efforts in the literature, those literacy programs that were identified were local, short-term and limited in numbers served. These were also the characteristics of the general adult literacy programs that include persons with disability we located through colleagues and then followed up to see if more information was available. Thus at the current rates, we believe it is fair to say that neither CBR nor micro-credit efforts are making a significant dent in the overall literacy rates for disabled adults worldwide.

Finally, while not the focus of this particular paper, we note that there is an established literature on the education of disabled children in most developed countries, based on formal systems of education available from early childhood to late adolescent. Within this literature, a smaller group of papers exist on the education of disabled adults, most describing programs specially targeted to adults with intellectual disabilities. These literacy programs however are intended to maintain or enhance skills already introduced during primary and secondary school. Comparable programs to maintain or sharpen skills of disabled adults from developing countries were not identified in our literature search. This is not surprising, given the fact that few of the millions of persons with disabilities in these countries have rudimentary education upon which to build further competencies.

Within International Development

Turning to the literature on adult literacy within the field of international development, (efforts to combat illiteracy among adults within the general population) we were also able to locate only limited numbers of references where disability is mentioned.

There is a wealth of materials in this literature on the benefits of literacy for impoverished and marginalized populations. Unfortunately, review of the literature yielded few examples of discussion of how adults with disability have been included in general literacy programs, nor discussion of the fact that adults with disabilities may present specific educational demands within such programs. (See for example: UNESCO 2003, World Bank 2009, World Education Forum 2000) What specific reference to persons with disability exist are rare, have appeared largely within the last two to three years in direct response to the UN Convention on the Rights of Persons with Disabilities and when included, lack specificity. Usually '*disabled populations*' are listed as one of several 'vulnerable' populations, grouped together with refugees, ethnic and minority communities and other 'at risk' groups with no further specifics discussed. While it can be assumed that some individuals with

disabilities are reached and served by general adult literacy programs, based on our findings, such outreach is not seen as a priority for those dealing with adult literacy. Within this literature, we failed to identify systematic efforts to take into account, target or include of adults with disabilities. Statistics on disabled adults as a distinct population is wholly left out of the major surveys intended to provide comprehensive understandings of literacy needs at the population level. (See for example: the International Adult Literacy Surveys (1994-2000 IALS), Adult Literacy and Life Skills Surveys (2003 ALLS) conducted in OECD countries, and the Literacy Assessment and Monitoring Programs (2003-2009 LAMP).

Interviews with Practitioners

Struck by the significant lack of published information, we supplemented our study by a series of informal, semi-structured interviews with 30 key policy makers, (15 working in international development on literacy efforts among at-risk populations such as women and refugees and 15 working in international disability and inclusive education) to identify policies or programs that may have been written up or that we may have overlooked.

These queries yielded few results. Most experts were unable to identify either disability specific adult literacy efforts or general literacy programs that sought out illiterate disabled adults as an important target group. Many were able to provide examples, usually anecdotal, of one or several small programs, that when tracked to their source, tended to be small ‘one off’ programs reaching several dozen to several hundred persons with disabilities over the course of a relatively short span of time. None cited by informants had been documented, monitored or evaluated and at least half of these were no longer running. Most colleagues interviewed had never thought specifically about the educational needs of persons with disability outside the classroom setting. A majority of those interviewed from the development arena – (13 out of the 15), reported that they thought that the educational needs of disabled adults were being addressed by organizations dedicated specifically to disability advocacy and programming. Regrettably, more than one expert in development clearly stated that the literacy needs of disabled adults were low priority – to be addressed only after literacy rates in the general population improved.

To summarize this entire body of work - only a handful of papers or reports exist on illiteracy among disabled adults and statistics are almost wholly lacking. In the literature, the overwhelming emphasis is on inclusive education for disabled children, with a concentration on bringing the youngest children into the classroom to begin primary school. Discussions of literacy almost immediately become focused on children with the emphasis even more specifically, on classroom based learning.

While reports of specific programs or studies may have been missed, we are confident that overall there is a striking lack of systematic attention, programmatic focus or theoretical frameworks to the literacy needs of disabled persons outside the classroom

and beyond childhood. There is currently not enough work in this area to form a readily identifiable field of study.

Poverty Alleviation and Literacy

Literacy rates among disabled adults are of particular concern because an impressive body of research clearly shows a strong feedback loop exists between literacy and poverty alleviation, empowerment, engagement in civil society and citizenship. This link is the reason why adult literacy has been at the very heart of so many international development efforts over the past thirty years, and the reason why annually, millions of dollars continues to be poured into efforts to ensure that marginalized populations –impoverished women, or the rural poor for example, acquire literacy and numeracy skills. (United Nations 2000) Indeed the Dakar Framework for Action includes as one of its six comprehensive goals a 50% improvement in adult literacy rates by 2015 – a goal which presumably includes all adults, including adults with disabilities, although neither disabled children or adults were specifically cited in the Framework. (World Education Form 2000)

Literacy for adults is understood to be a continuum of competencies. Basic skills, such as the ability to write one's name, are followed by 'functional literacy' which UNESCO, in its Education for All initiative defines as 'the ability to engage in all those activities in which literacy is required for effective functioning of this group and community.'"(UNESCO 2006) Importantly, functional literacy acknowledges that an adult's ability to learn to read, write and compute is not linked to school based instruction and thus, offers a second chance to people not fortunate enough to acquire literacy skills through classroom-based education in childhood. Concepts and implications of providing literacy skills to for example, impoverished women, to help break the cycle of illiteracy and poverty, are particularly relevant for disabled adults.

Literacy of course, has established benefits beyond economic ones. For example, improving basic literacy skills for women has direct health and nutritional benefits for not only themselves but for their children. (WHO 2008) The concept of health literacy – having enough literarily skills to acquire and act upon new information for health and well being, is certainly relevant to persons with disabilities and their families. (Kickbusch 2001; Wallerstein and Bernstein 1994)

On a broader plane, the various functional values of literacy contribute to empowering individuals by expanding their choices, thus reducing their dependency and vulnerability.(WHO 2008) Literacy allows poor and marginalized groups to take necessary steps to ensure that their rights are not violated – including the right to make decisions for themselves and their families, to protect themselves from illegal or unwarranted abuse within the legal system (for example, having their property 'grabbed' or signing away their rights or property), and the fundamental right to participate in civic affairs to bring about social and political change.(UNESCO 2002)

Thus literacy enhances social participation, and contributes to reducing stigma, prejudice and discrimination. (UNESCO 2005)

This association between poverty alleviation and literacy is especially significant for persons with disabilities. A growing literature clearly shows that poor people are disproportionately more likely to be born with or become disabled through lack of access to health care, poor nutrition, poor housing, dangerous working conditions and violence; and poor people who have become disabled are more likely to become destitute. (Yeo and Moore 2005, Braithwait and Mont 2009) This poverty not only affects persons with disabilities themselves, but has serious implications for households with disabled members. (Erb and Harriss-White 1999; Elwan 1999)

Missing from this growing body of disability and poverty studies however, is serious attention to the role that illiteracy plays in perpetuating the poverty cycle. The ILO estimates that unemployment rates for persons with disabilities who are able and willing to work still hovers above 80% in most developing countries. (ILO Website 2009) Denied a basic education, and unable to gain literacy skills as adults, the lack of basic literacy and numeracy skills undoubtedly is an impediment for many to finding a first job or advancing to a better position. Additionally, millions of persons with disabilities are part of the informal, rather than the formal economy, self-employed and earning their income through one or several different jobs. (Hoogeveen 2004; Braithwaite and Mont 2009). Illiteracy among these must limit many from developing their own income generated activities and leaves them at the mercy of those who see their limited literacy and numeracy skills as a way to take advantage or cheat them of their time, labor or wages.

While this lack of education is clearly identified as an issue in limiting employment options, there has been strikingly little discussion in the literature of the actual impact of illiteracy on disabled peoples' ability to gain the skills and opportunities they need to effectively take part in the jobs market. While increased literacy rates for disabled adults will not single-handedly eliminate poverty, we believe it is a critical 'missing element' in many current discussions on the disability-poverty cycle within and beyond the disability community.

Next Steps

Given all this, where does one start? There is no doubt that basic data on literacy need to be gathered by researchers, policy makers and advocates to provide accurate information upon which to allocate resources and plan for the future. Data on literacy for the general disabled population as well as data disaggregated by type of disability and factors such as gender and membership in ethnic and minority groups are all needed. While disability-specific research is needed, equally important, is putting a disability component in broader population and community based research on literacy and educational statuses, household poverty, health and well-being to better understand how the literacy status of disabled adults impacts economic development

efforts. As is true of all other international development efforts, no single program will serve everyone. Both general and disability-specific literacy campaigns will be needed. DFID's twin track approach –provision of both disability-specific programs and inclusion of persons with disabilities in general development efforts is particularly relevant here. (DFID 2000)

We anticipate that millions of adults with disability can be included in current and future general adult literacy campaigns at little or no significant costs or with only minor changes to current programs. Research from other fields, such as global health, show inclusion of persons with disabilities in efforts such as HIV/AIDS outreach have been successful in including many persons with disabilities in general community initiatives. (World Bank 2004)

At the same time, persons with certain types of disabilities will need specialized programs – for example, targeted initiatives for teaching Braille to blind adults or having instructors fluent in sign language to teach deaf adults. Literacy for individuals with intellectual impairments needs to be done at a pace which those receiving instruction can benefit from. However, it is important to emphasize that the needs of subgroups within the larger disabled population are predictable and can be anticipated, prioritized and budgeted for. Even if such targeted literacy programs reach only certain subgroups of the overall number of illiterate disabled adults in a community, the effects will be cumulative. Over the course of time, literacy levels within the general disabled population will rise – and in so doing, literacy among disabled adults will become the norm and not a striking exception to the rule.

While literacy for both men and women with disabilities is important, special attention to women with disabilities – both through inclusions in on-going women's literacy campaigns and through special outreach programs for women with disability – is of critical importance. Likewise, it must be kept in mind that disability is a cross-cutting issue. Literacy programs and policies intended to reach vulnerable groups – for example, members of the local ethnic or minority community, people in refugee camps – should be including disabled adults as members of these communities.

Finally, we have concentrated here on making a case for basic literacy skills for disabled adolescents and adults. Additional attention will be needed to provide higher levels of skills to persons with disabilities once basic literacy and numeracy have been mastered. Just as many programs which began by providing basic literacy skills to poor women or refugee populations have expanded over the years to build competencies towards more advanced goals such as degrees or specialized certificates – (business skills, computers, and so forth), systems of education for disabled adults should be envisioned that will move people from illiteracy to functional literacy and then continue to build skills and abilities to allow them to expand their options.

Finally, rather than re-inventing the wheel, it is imperative that those who work on global disability issues and on inclusive educational efforts start a meaningful

dialogue within and between officials, advocates, program and policy experts and funders who already have established experience in working on general literacy, poverty alleviation and empowerment issues. Likewise, many long established insights and techniques developed in the classroom to teach disabled children can also be called upon to benefit adults attempting to acquire the same skills. Expertise already exists on adult literacy within international development circles and on disability-specific and inclusive education within the fields of education and disability studies.

The Role of DPOs and NGOs

There is an important role to be played here by disabled people's organizations (DPOs) – groups run for and by persons with disabilities, as well as by NGOs that advocate on behalf of and provide services to persons with disabilities. These groups already constitute a strong voice for the rights of persons with disabilities in many countries– and facilitate outreach to persons with disabilities in their communities. DPOs and NGOs can provide leadership and expertise for adult literacy, working both independently and in collaboration with government ministries, UN agencies and development organizations to ascertain the levels of disabled adult literacy and to identify the educational needs of the disabled populations they represent.

We suggest that such organizations have additional roles. Certainly one is to build interest and demand for literacy skills among the disabled adults that their organizations represent. Additionally, they can also take leadership in reviewing all poverty alleviation programs that include literacy programs to identify where and how persons with disability can be included. Training and advocacy to increase awareness of disability among those who already work on adult literacy issues within international education and development circles is equally important. Raising disability awareness is not a new role for many DPOs and NGOs which already have experience providing disability awareness to policy makers, legal experts and health professionals. Furthermore, recent efforts to foster inclusive education in schools in many countries means that links with educators and ministries of child welfare have already begun to be established. Working with literacy experts, disability organizations can help add a disability component to local projects as well as develop guidelines and monitoring and evaluation tools to ensure that local adults with disability are also being adequately reached and served.

DPOs might go further – leadership in most DPOs are themselves literate – often having benefited from inclusive education efforts or specialized schools with insights gained by their own experiences. These advocates might consider leading efforts to organize disabled adults and other volunteers as well as disabled high school, college and university students, to help teach fellow members of the disability community. For example, students at a regional high school for the Deaf could provide literacy classes in sign language to illiterate deaf adults in the surrounding community; blind university students could teach Braille to blind adults in the surrounding community. To do these things, DPOs and NGOs will need additional funding and support from

ministries of education and economic development as well as UN and NGO groups that work on poverty alleviation fields, as most disability organizations already run on shoe-string budgets. The knowledge and networks such disability groups bring to the table would be invaluable in reaching and educating many.

Conclusion

The link between literacy and poverty alleviation is already firmly established within international development circles. Just as great strides were made in reducing poverty and improving child health when concerted efforts were made to provide basic literacy skills to adult women, literacy for disabled adults should be considered a key component in addressing the on-going cycle of poverty and social exclusion faced by millions of disabled adults.

Throughout the existing literature, we found discussions, research, policy and pronouncements about education of persons with disabilities consistently were framed in terms of 'school-based' education, with children either the sole focus of attention or discussion turning quickly to children, classrooms and teachers. Part of the reason why this is the case, is that there has been a strong and highly effective collaboration between parents, teachers and disability advocates which has given increasingly high visibility to the issue of access to inclusive education. There is very little comparable attention to learning for disabled adults in the developing world – and there is also little attention to education or the acquisition of skills throughout the lifespan. (It is also possible that some policy makers and educators who know little of disability think of persons with disabilities only in terms of 'children' or 'childlike' rather than as fellow adults. (Groce 2006)) And while there is welcome attention to increasing enrollment of disabled children in schools, there is strikingly little in the literature about those children who are not yet reached by inclusive education efforts despite the fact that a significant proportion of disabled children will not be reached by inclusive education programs or by specialized schools before they 'age out' of formal educational systems.

We argue that education takes place throughout the lifespan and beyond the doors of the classroom. The scope of 'inclusive education' must be expanded to ensure that basic literacy is made available to those persons with disabilities who have not been fortunate enough to receive a classroom education. And once basic literacy is reached, we argue that there is need for additional education to ensure growing levels of competency and choice for disabled adults. For this reason, we appeal to those involved both in disability education to think beyond the confines of childhood and beyond the walls of the classroom. The knowledge that such experts and advocates possess is invaluable to reaching the vast majority of persons with disabilities who live – and who will continue to live for decades to come - unable to read and write.

There is a need for more research to define the scope of this problem and to identify innovative and inclusive approaches to providing basic literacy skills both as part of

both general adult literacy campaigns as well as through disability-specific adult programs. Additional attention is needed to the monitoring and evaluation of such programs, but we already have an idea of the parameters of the problem and delay should not be an option.

We anticipate that no single approach or specialized program will reach all adults with disabilities – rather, a combination of approaches will be needed to reach this diverse and severely underserved majority of the world’s disabled citizens. We fully recognize that this task will involve time, energy and resources that are already in short supply. Moreover, it is imperative the needs for literacy and broader education for disabled adolescents and adults not be framed as an issue competing with the inclusive education movement. The issue is not either/or but rather the importance of expanding efforts and resources to provide this missing element. Furthermore, we recognize that the broader field of adult literacy within international development already suffers from low priority and lack of resources within the broader EFA effort. However, education for adults with disabilities should be part of this broader adult literacy agenda. The benefits of improving the literacy and numeracy skills of millions of disabled adults far outweigh the costs needed to address this issue. Without such an effort, the objectives of the Millennium Development Goals will not be reached – and the abilities of millions of disabled adults will continue to be needlessly limited and overlooked.

Appendix A

The following journals and UN, DPO and NGO websites were reviewed for information or references to disabled adults and literacy:

JOURNALS

Disability Journals

- Disability and Society
- Disability and Rehabilitation
- International Journal of Disability, Development and Education
- Journal of Disability Policy Studies
- Journal of Intellectual and Developmental Disability
- Journal of Intellectual Disability research
- Journal of mental Health research in intellectual disabilities
- Journal of Religion, Disability and Health
- Journal of Social work in Disability and Rehabilitation

Adult Education/ Continuing Education Journals

- Adult Education and Development
- Adult Education Quarterly
- Journal of Adult Education
- New Directions for Adult and Continuing Education
- New Horizons in Adult Education and Human Resources development

Special Education/ Inclusive Education Journals

- British Journal of Special Education
- Current issues in education
- Educational Action Research
- Educational Research
- European Journal of Special Needs Education
- International Journal for Educational and Vocational Guidance
- International Journal of disability, development and Education
- International journal of inclusive Education
- International journal of lifelong learning
- International Journal of special education
- Journal of Research in special educational needs
- The journal of special education

Websites

United Nations Websites

- UNITED NATIONS COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>
- UN ENABLE <http://www.un.org/disabilities/default.asp?id=1228>
- UNESCO Flagship on Inclusive Education
http://www.unesco.org/education/efa/know_sharing/flagship_initiatives/disability_last_version.shtml
- OHCHR-Disability

- Committee on Economic, Social and Cultural Rights: General Comment No. 5 on Persons with Disabilities
- Committee on the Rights of the Child: General Comment No. 9 on the Rights of Children with Disabilities
- UNAIDS
http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2009/20090409_Disability_HIV.asp
- World Health Organization – Disabilities
<http://www.who.int/topics/disabilities/en/>
- Women Watch (part of the UN Inter-Agency Network on Women and Gender Equality) <http://www.un.org/womenwatch/enab/>
- UNHCHR – Human Rights and Disability
- The World Bank and Disability
<http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,menuPK:282704~pagePK:149018~piPK:149093~theSitePK:282699,00.html>
- FAO Database on the Rural Disabled
- International Labour Organization (ILO) Skills and Employability Department (Inclusion of Persons With Disabilities) http://www.ilo.org/skills/areas/lang--en/WCMS_DOC_SKL_ARE_DBL_EN/index.htm

Disability Networks and Organizations Websites

- International Disability and Development Consortium (IDDC)
- Enabling Education Network
- International Disability Alliance (IDA)
- Rehabilitation International (RI)
- Disabled People International (DPI)
- World Blind Union
- World Federation of the Deaf
- The World Federation of the Deaf/blind
- Inclusion International
- World Network of Users and Survivors of Psychiatry (WNUSP)
- European Disability Forum (EDF)
- Ecumenical Disability Advocates Network (EDAN)
- Disability and Development Co-operation, Germany
- PHOS
- Disability Awareness in Action
- Mobility International USA
- Independent Living
- ICEVI
- Motivation

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