

Disability, poverty and education: perceived barriers and (dis)connections in rural Guatemala

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This paper engages with the impacts of disability on the formal education of disabled people in poor rural areas. Reporting on qualitative ethnographic work in Guatemala, adults with a physical impairment provided retrospective accounts of their educational trajectories. Findings highlight multidimensional and dynamic barriers to education confronted by all poor people, but which often intensified for disabled people. These met a host of disability-specific barriers cutting across social, physical, economic, political and personal spheres. Findings report how in the face of more persistent basic needs and costs, education had a high opportunity cost, and often could not be sustained. Disabled parents also came to prioritise the education of their children translating into limited or no school re-entry for these parents. The paper concludes that engagement with temporal and context specific (but fluid) spaces of poverty is necessary, because it is within these spaces that disability and education are constructed and lived, and within and through which barriers emerge. Cross-sectoral efforts are needed, addressing educational barriers for *all* poor people indiscriminately, while targeting families to remove obstacles to other basic needs competing with education. Critically, efforts are needed to ensure that educational outcomes are linked to immediate contributions to the family economy and welfare through work.

Keywords: Global Disability, Poverty, Global South, Majority World, International Development, Inclusive Education

Introduction

The right to education is a right that continues to be echoed globally, constitutive for many of personal, social, economic, cultural and political development in an increasingly interconnected world. Education is also frequently considered to be one of the basic mechanisms through which people can be lifted out of poverty, and hence a matter of social justice (Terzi, 2010).

The notion of education as a basic human right has been articulated in a number of declarations and treaties, with many governments progressively signing up. The first reference to education was in 1948 through the Universal Declaration of Human Rights. Since then, numerous other treaties emerged: the Convention against Discrimination in Education (UNESCO, 1960); the International Covenant on Economic, Social and Cultural Rights (UN, 1966); the Convention on the Elimination of All Forms of Discrimination against Women (UN, 1981); the Convention on the Rights of the Child (UN, 1989); the World Conference on Education for All (EFA, 1990); the Dakar Framework for Action (UNESCO, 2000); and more recently the Jakarta Declaration in 2005. The focus on education in the global South has featured in most of these declarations on account of the disproportionate poverty and barriers to education in such contexts (see Maile, 2008). The Millennium Development Goals (MDGs) have also garnered substantial support for education in the majority world through Goal 2, committed to ‘ensuring that children everywhere, boys and girls alike, will be able to complete a full course of primary education’ (UN, 2000).

Attention to the education of disabled people as a human right, though, has not been so forthcoming (Miles and Singal, 2009; Singal, 2010). It was in fact only in 1985 that the Universal Declaration on Human Rights included disabled people in its content, and only in 1990, through the Education For All (EDA) initiative (UNESCO, 1990) that disability was finally considered a core theme. But discourse around disability rights and inclusive education has stepped up over the past two decades, thanks to a number of disability-specific treaties, policies and conventions (see Miles, 2007). These have included: the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993; the Salamanca statement by the UNESCO in 1994; and the UNESCO Policy Guidelines on Inclusive Education in 2009. The most notable has been the UN Convention on the Rights of Persons with Disabilities (CRPD) the very first international disability rights instrument, received with much enthusiasm by the international disability movement.

The subject of disability in the global South has progressively featured in recent years, first of all based on the sheer numbers in these geopolitical spaces. It has frequently been suggested that some 80% of the 1 billion disabled people round the globe are located in the so-called majority world (WHO and World Bank, 2011). But it was the linkages created between disability and international development that have provided the greatest impetus for seriously considering the condition of disability in the global South. Disability and poverty are often said to be caught in a mutually reinforcing cycle, and that some 1 in 5 of the world’s poorest people are disabled people (see Groce et al. 2011). This has provided some leverage for those lobbying to include disability in a development sector, which in theory prioritises poverty and its reduction. Article 32 of the UNCRPD addresses international cooperation, motivating states, international organisations and civil society to ensure ‘that international cooperation, including international development programmes, is inclusive of and accessible to persons

with disabilities'. While not a legal document, and hence non-binding, and while it is too early to evaluate its impacts in practice, the publication of the very first World Report on Disability by the WHO and World Bank in 2011, also provided an opportunity for putting disability on the global policy map, while affording the global South some visibility on the disability radar. The education of disabled people in the global South is addressed directly and indirectly in the UNCRPD, for example through Article 7.1 which obliges parties to 'take all necessary measures to ensure the full enjoyment by disabled children of all human rights and fundamental freedoms on an equal basis with other children'. The World Report on Disability also devotes an entire chapter to the education of disabled people.

But the situation in practice remains far from ideal. Disability remains stranded on the margins of development policy, research and programmes, including poverty reduction and education programmes (Grech, 2011). Disability is often neither mainstreamed within existing programmes (despite the growing rhetoric of 'inclusive development') nor targeted in disability-specific ones. This exclusion from development is as practical as it is ontological, a situation whereby disability is not yet seen as a development issue or a questions of rights, but instead continues to be cast in the medical and/or charitable sphere. The absence of disability from the MDGs is perhaps emblematic of the gross exclusion and a serious concern when these goals continue to guide most poverty reduction and development policies, funding and projects (Groce, 2011). While the rhetoric of 'inclusive education' and 'education for all' have contributed positive shifts in discourse and policy, in practice, millions of disabled people are often deprived of any education, especially in the global South (Miles and Singal, 2009; Groce and Bakshi, 2011). Rough estimates suggest that 90% of disabled children, especially girls, do not attend school in the global South, in particular those from indigenous and rural areas (UNESCO, 2007); and that those who do are more likely to drop out of school than any other vulnerable groups even in countries with high primary school enrolment rates (WHO and World Bank, 2011). These figures are perhaps unsurprising when one considers that globally, 61 million children of primary school age are out of school (the majority in the global South, notably Africa) (UNESCO, 2012).

Despite these figures, disability discourse including that on inclusive education continues to be fabricated in the global North and transferred to the global South, with little or no alertness to context or culture, or how this discourse is framed, applied (or otherwise) or even resisted in practice (Grech, 2011). Overall, there remains a serious lack of empirical material on disability in the global South, in particular qualitative research listening to and prioritising the voices of disabled people in extreme poverty. Information on the relationship between disability and poverty across a range of areas, including livelihoods and education is still scarce. Research on disability in rural areas remains notoriously absent and regions such as Latin America continue to be seriously underrepresented. Many of the countries within this region are cast into the middle income bracket, implying that they are often unprioritised by

the development sector as a programmatic and research region. Funds continue to determine what research is done, where, and how, with research institutes and universities in the global North (and increasingly in the global South too) led by the scent of money following closely the methodologies desired and often prescribed by these funding bodies. And much of this, hardly calls for critical work, including around hegemonic notions, be it ‘inclusive development’ or ‘mainstreaming’ and hegemonic practices.

This paper reports on qualitative ethnographic work in rural Guatemala with the set objectives of: understanding the perceived barriers to formal education for disabled people; and exploring how education, poverty and rurality are connected for disabled people. The overall aims of the paper are: to contribute understandings into the disability and poverty relationship in rural areas; inject a Southern focus to the growing Northern debate on ‘inclusive education’; and to support theoretical, policy and practice developments in education and other areas that are culturally and contextually informed and sensitive.

Methodology

This exploratory study was rooted in the qualitative tradition adopting an ethnographic approach. Ethnography is defined as ‘immersion within, and investigation of a culture or social world... to make sense of public and private, overt and elusive cultural meanings...of *making the strange familiar*’ (Goodley, 2004:56, italics in original). A total of 25 adults (15 men and 10 women), ages ranging from 19 to 48, with physical impairments, were purposively selected from a sampling frame provided by key local gatekeepers, notably local disabled people’s organisations (DPOs). These hailed from rural areas, including mountain villages, and 16 were indigenous people. The choice of location as well as indigenous participants was based on the fact that indigenous people in rural areas remain underrepresented in poverty, disability and education literature. Twelve participants had congenital impairments and the remaining ones had acquired impairments, the latter also a result of accidents, untreated medical conditions, violent assault and shrapnel from the civil war. All participants, though, self-defined as disabled and poor people.

The main methods employed in the study were in-depth unstructured interviews with disabled people. This formed part of the bid to highlight and prioritise voices, knowledge and perceptions- inspired also by decolonizing methodologies (Tuhiwai-Smith, 1999). Interviews lasted between one to two and a half hours, with many of the participants interviewed repeatedly, sometimes up to 3 times. Interviews were held in Spanish making use of a translator/cultural mediator with 9 of the indigenous participants who spoke two different languages. Translators were experienced organisational gatekeepers and cultural mediators

hailing from these same communities, with experience in translation for research purposes. Translators provided invaluable discussion and input also into the analysis. Interviews were held in the homes of participants, recorded and later transcribed.

Informed consent was obtained from all participants and their families orally (to account for illiteracy) and recorded, anonymity and confidentiality ensured, and their rights (including to withdraw at any time) articulated in as clear and contextually and culturally sensitive manner as possible. The analysis started in the field and was ongoing, employing thematic analysis defined as a method ‘for identifying, analysing, and reporting patterns (themes) within data’ (Braun and Clark, 2006:6), in this case the narratives. Thematic analysis provided a flexible, inductive and continuous process of engaging with the narratives, seeking out patterns across the words of the participants, while ‘organising’ them into fluid categories or themes. The findings below present the voices of participants. All names have been changed to protect their identity.

Key findings

Education: perceived value and contributions to the family economy

The subject of education emerged frequently among participants, and it was clear from the start that education for most of the poor meant primary education and at best secondary education in public schools. Education for all participants meant mainstream public schools, since private schooling, they stressed comes at a hefty cost and is unavailable to them. Participants’ understanding of education was strictly formal education, and they appeared to have little or no knowledge of the existence of non-formal education or community-based initiatives. Education appeared to be a greater concern among those who were younger adults, those who did not have young families, and almost invariably those living closer to towns or cities. These were places where access to education was marginally better, skilled formal jobs were concentrated, and where some or other formal education was more likely to be a pre-requisite for paid work. Jose Manuel, a 22 year old indigenous man highlights the linkages between schooling and paid work in urban areas:

Sometimes I think I should have a chance, I can even see the school from up here, and my dream is to maybe find work in town, in a shop or something, but today many ask for at least primary school (Jose Manuel)

Consideration of and references to education as a perceived benefit indeed depended on age as well as personal and familial circumstances. Many of the participants, especially those with young families, felt that their chance had come and gone, prioritising instead the

educational needs of their children (none of these had an impairment). The desire was to have at least the eldest complete secondary education, with the hope that this child would go on to work and help support the family economically. In the case of disability, this pressure became stronger, especially when this labour was meant to replace that of the disabled household head and hence the main breadwinner. This situation was also clearly gendered, with participants often highlighting how they prioritised the education of the eldest son, frequently at the expense of that of daughters. Men, they stated, stood a better chance of finding paid work, and hence education was seen as a better investment, including by mothers:

Girls can help in the house. We are investing all we have so our son can finish secondary school, so like that he can find work and help us out... a girl, can maybe find work washing and cleaning, but not easy and always too little money (Elena)

Overall, participants perceived a number of benefits to education, many of which, it was clear were bound to the predicament of poverty; the absence of any formal social protection, typical in the lives of the poor (see Barrientos and Hulme, 2010); and what they believed about education, as opposed to what education actually delivered in practice (see below). To them, these included: the possibility of a less arduous job; more sustainable and paid livelihoods (as opposed to erratic activities such as seasonal agriculture); and better ability to contribute to household welfare. More than anything, education, they insisted, has high symbolic value for parents- of love and struggle- who despite the hardships of poverty expect to provide at least a few years of schooling for their children. It was also clear that to some extent, education was also a source of cultural capital (Stromquist, 2007), but within the confines of a poverty that can hardly be shifted or escaped:

Maybe suffer less, not have to break their (children's) back like I did, maybe know they can have some money and eat every month without worrying, and when they have their own family to be able to feed, clothe and educate them... maybe also be respected even in this small community (Alejandro)

Complex, dynamic and heterogeneous barriers

Participants documented multidimensional barriers in accessing as well as continuing their education as disabled people. Some articulated how they found it much harder to start school, while those who were already in school (before the onset of their impairment), had lower transition rates, resulting in lower school attainment overall (see also Filmer, 2005). The net result, though, was the same in the both cases- interrupted education. Twelve participants, nine of who were indigenous, had never been to school, while those who did, reported

completing only up to three years of primary school as children. None of the participants were in education at the time of interviewing.

While participants highlighted that disability was the final blow to education, they were quick to suggest that barriers to schooling were a common reality for all poor people, suggesting that one needs to engage with these in order to frame and understand the situation for disabled people (I highlight these below). (I highlight these below). Indeed, the sight of children out of school wondering the streets during school hours in Guatemala is as common as the painful sight of poverty. Small children, especially in rural villages or towns, if not helping with household tasks or running in the streets, are instead working in arduous and dangerous conditions, whether selling food in the chaotic bus terminals or aboard buses, shining shoes, parking cars, begging, or delivering goods such as gas tanks and water many times heavier than them. This is an existence lived everyday in public, side by side by schools, government departments and police, a reality that no one questions, and even less intervenes in.

These barriers not only remained in place, but often intensified following the onset of their impairment. Participants, though, highlighted how they also encountered disability-specific barriers, predicated to various degrees on the presence of their impairment and interactions between their bodies and a host of disabling barriers:

It is bad for everyone here, the roads, the mud, no school, no money for books...it gets worse with your body like mine because the roads become a death trap, and then you have other problems for yourself ... so when this illness (disability) came, it killed all hope (Maria)

Over the next two sections I present an overview of these generalised (shared) barriers, followed by disability-specific barriers to education. These are not dichotomised here, and neither are they presented in an organised, linear or static way. Instead, they are fluid, complex and constantly interacting, and often hybrid, depending on a range of personal, social, gendered, historical, economic, racial, ethnic, linguistic, political, geographical and other lines. These point some attention towards the recognition of the heterogeneity of disability and the disability experience (see Garland-Thomson, 1997; Grech, 2011) including in education, while opening spaces for a host of intersectionalities as well as different trajectories shifting spatially and temporally. The implication is perhaps that these barriers to education and aspects of the disability experience can only be reasonably understood over time and space, are (re)negotiated and dynamic, and can hardly be captured in static one size fit all models. For example barriers were particularly intense for those with mobility-related impairments who could not navigate the dirt tracks; those in isolated rural and indigenous areas very far away from schools; and participants with no working family member who

could cover the costs of their education. Barriers also became more intense at times in the year when food costs increased due to food shortage prior to harvest- the ‘hungry period’. Patriarchal patterns and machismo, a hegemonic but dynamic masculinity in certain areas (see Connell and Messerschmidt, 2005), met gendered division of labour and the disproportionate burden of productive (including unremunerated) work as well as child rearing, and beliefs about female education (see above), with the implication that access to and maintaining education was much harder for female participants. Mirna, a 28 year old indigenous woman articulates these gendered concerns:

As a girl, my family felt it was easier to pull me out, perhaps not thinking much of the value of it, we had money problems, or maybe someone will take care of me they thought...as an adult, I now have to cook for my siblings and their children and wash clothes (Mirna)

Overall, access to education had been much harder for indigenous participants, especially those who were of school age and residing in the mountains during the most violent period of the civil war (1979-1984). Many had been forced to flee as schools and villages were razed to the ground, and livelihoods were destroyed, frequently to never recover again. In the face of violent conflict and displacement and their long term impacts, the bid to survive, it was clear, negatively impinges on possibilities of initiating and continuing education (Pisani, 2012), again positioning understandings of barriers within the broader socio-economic, political but also historical context, as these traverse the present and the future tied together by a poverty that, though changing, has always been there.

Poverty-induced barriers

Participants spoke about a myriad of barriers to education, part and parcel of life in poverty for all, documenting how these hurdles intensified, becoming disabling barriers when met by their impaired bodies and the needs emanating from these- the moment where the unruliness of bodies with impairments confronts the hegemony of ‘the norm’ and ‘the normal body’ (Michalko, 2002; Davis, 2010:3). The body materialises in a context where eating, basic pain relief, livelihoods and indeed survival hinge on physical strength- what McRuer (2006:90) would call a ‘compulsory able-bodiedness’:

Geographical isolation and no schools in distant areas: In Guatemala, there remains a clear bias towards urban areas and non-indigenous populations in school provision. When schools are available in rural areas, they only offer education till third grade (8-9 years of age). Secondary education becomes virtually impossible for the poorest who are often unable to

pay for the costs of sending their children to school elsewhere (towns and peri-urban areas).

Poor infrastructure, extreme weather conditions and transportation problems: remoteness and physical isolation meet dirt tracks and pathways which are especially inaccessible and dangerous during the rainy season. The lack or absence of affordable and reliable transportation together with these infrastructural barriers constrain mobility, translate into long walking distances in perilous conditions, and enhance costs (including time) of those seeking alternatives e.g. those forced to book a private vehicle. For disabled people, these barriers intensified, especially for those who could no longer negotiate this harsh terrain on foot, or needed help with getting up and down the bus, and who need to be picked up again:

You can barely walk when your body is ‘full’ and functioning, stones, mud, holes and people get hurt... so getting to school was always a problem especially when it rains...but when I had my leg amputated, I could barely mobilise in my home, and have no vehicle to take me there (school)...that was the end (Alfonso)

Lack of running water, sanitation and electricity: these not only contribute to the urban bias in schools while maintaining the rural ones in deplorable and unhealthy conditions. They also mean that within their households, children are busy with tasks such as collecting water, often from very large distances. For some participants, catering for these activities became more time consuming and problematic on account of their impairments, impacting their education even further.

Overcrowded schools and poor quality education: teacher absenteeism, excessive holidays, insufficiently trained teachers, unequipped schools (e.g. benches and desks), lack of teaching materials, difficulties recruiting in isolated rural areas, and a high turnover of poorly paid teachers are well documented problems in Guatemala (see McEwan and Trowbridge, 2007). These impact not only students, but also teachers, hindering at various points the accumulation of experience and learning on the job. The education provided, as participants recounted, is also often of little relevance to the students’ lived realities and learning needs (in particular ones creating opportunities for work), inspiring in turn little hope or faith in the education system. The following quote captures this:

The schools are rubbish, don’t teach anything, teachers don’t go to school too...the children don’t learn anything... especially that can help you get work...there is one teacher always drunk on the streets... fuck this education (Santiago)

The need for the labour of children at key stages of the agriculture cycle: particularly on family owned plots of land, means that education is interrupted at key times during the year (e.g. harvest). Labour pooling by all family members, including small children at specific

points of the agricultural cycle, is a common practice. This work is not necessarily exploitative, but a means of ensuring adequate labour power to produce enough food to pull the family through the year. Indeed, this is a design many schools in rural areas are prepared for, and even accommodate, not least because teachers are sometimes working their own land. Disabled people are not always excluded. Participants, especially those with some or other mobility, highlighted how they continued to contribute to supporting the family's subsistence needs through tasks that were lighter and manageable, such as husking, tasks they performed since their childhood.

Costs of schooling: while public schools are free, shoes, books, uniforms (or clothing adequate for school), transportation and food are not. Formal safety nets providing assistance with these costs are inexistent, while livelihoods are often fragmented. Participants stressed that no matter how low these costs are, they are often exorbitant for poor families with no savings, little or no cash inflow, and struggling with other basic needs, notably food and health care. The situation was particularly precarious for families with more than one child in school. Studies estimate these costs of primary education in Guatemala to be as high as 12% of the basic food basket per month (Porta Pallais and Laguna, 2007 cited in Otto, 2008). Participants highlighted how the poor are frequently pushed to prioritise between the costs of feeding and those of schooling, and how comprehensibly, they often choose to eat. Following their impairment, catering for the costs of education became even more prohibitive, as families now faced health care and other costs, initiating other spirals of priority, while pushing education further down (see below):

Too much money, the books, the shoes and everything else...when you are struggling to even put food on the table, to buy a pill, and there is never any help with these, the children suffer, because a good parent first feeds... what use is education for a sick or dead child? (Estela)

Language and cultural barriers: many indigenous people cannot speak Spanish (or well enough), but most schools teach in Spanish, symptomatic of an educational system strengthening the cultural value of the elite (see Bourdieu & Passeron, 1977). This, as participants emphasised, strengthened indefinitely the ladino/indigenous material and cultural divide in a context where 'to speak a language is to take on a world, a culture' (Fanon, 1967: 25). The dominant use of Spanish reflects the use of a language that is not only for cultural consumption by the ladino dominant minority, but that also serves as a means of subjugating those at the margins- even of language- a marginalisation that has long colonial roots and that diffuses into the present and the future:

...the public schools are for the ladinos, not for us, so we and our children are even

more disadvantaged, even with language... my parents have a similar story, of the whites and us, of those with Spanish lineage who dominate us, and my children will tell the same one too (Carlos)

Few or no concessions by employers: poor people almost always labour in informal settings e.g. construction or agriculture. This means that they are not registered and not entitled to labour rights including leave, sick leave, or compensation, while employers have no legal obligations towards them. The urgent need to survive means the poor have to take up any work, whenever and wherever it crops up, interrupting any projects, including education. Participants documented how to employers, the poor are little more than an endless labour pool ready to give up their bodies for exploitation and for abuses - bodies already rendered 'docile' (Foucault, 1977) by and through the work they have to perform. For disabled people who face even stronger barriers to finding work, and who are pitched against this able-bodied pool of workers, these concessions are even harder to come by. On the contrary, as participants highlighted, they are often made to feel grateful for a stint of work too often paid less than their peers with no disability.

Disability-specific barriers to education: education is not for every 'body'

Participants explained how all the barriers above remained present, meeting a host of new disability-specific hurdles, especially for those with more serious and chronic impairments. They spoke about innumerable obstacles they had confronted especially as children:

Long periods of hospitalisation: for those who did have access to medical care, education was sometimes interrupted during treatment, and they were then unable to go back, not least because demands and priorities within the family had changed- in particular the need to cater for their health care costs and to cover the loss of their contribution (if any) to the household income.

Invisibility of disabled people from public spaces (including schools): not too present in public spaces, the invisibility of disabled people, normalised and maintained their exclusion, in turn feeding back into the 'ontological invalidation of disabled people' (Hughes, 2012: 17)- or rather the notion that disabled children are not meant to be in schools in the first place:

Out of sight...you don't exist, so no place, even schools do not expect you to be there!
(Mario)

Direct and indirect costs: health care and medication in particular absorbed all the household resources, and together with loss of labour (of the disabled child or any other family member providing care), little or no money was left for schooling. Compounded by the costs of other/more basic needs, including food, poor families were forced to prioritise, and again, participants recounted, the education of the disabled child often had to be interrupted:

You medicate, you get some pain relief, you eat, you get a few more days of life...so school is gone, that easy (Delfina)

Architectural and training barriers- non-inclusive schools: many of the schools in rural areas, as one can clearly witness, are physically inaccessible, embodying what Imrie and Kumar (1998) in the global North would call ‘design apartheid’. Dirt floors meet packed classrooms, no ramps, and no accessible entrance from anywhere. This is an inaccessibility pronounced and witnessed in most public (and often even private) structures around the country e.g. shops, hospitals, government offices, service providers completely fenced off for disabled people. Two participants recounted how as children, after their parents had managed to convince and even beg teachers to allow them into class, they were unable to negotiate mobility with their wheelchairs within these schools, and had had to give up. Teachers also have little or no disability-related training and have no access to adapted teaching materials (e.g. Braille). Participants stressed that no authority seems to monitor and enforce laws on accessibility. Even more basically there appears to be little local knowledge or concern for national disability policies on inclusive education and even disability rights not only by schools or municipal authorities (see Tobar Estrada, 2013), but also, as became evident in this study, by disabled people themselves and their families.

Problematic attitudes: participants documented how the normalised invisibility of disabled people from public spaces was partly a result of and fed back into exclusion from schooling, often manifested in outright rejection. Combined with factors such as low salaries of teachers, overcrowded classrooms and lack of training, as disabled children, participant stressed, they were simply seen as a nuisance- with schools unwilling to accommodate them even through minor adjustments such as a ramp. Reflecting on the situation in the present, they emphasised that not much can ever change when mainstream schools continue to insist that disabled children’s place is in special schools but when these are often inexistent in rural areas, are privately provided, and reach only a tiny amount- generally affluent urban children in the capital city. In fact participants hardly knew of the existence of these schools. Participants also spoke about problematic attitudes among peers during their time in school, describing these as reactions of ‘shock’ or ‘surprise’ at the ‘disabled presence’ (rather than the intention to discriminate) (see also Ghai, 2006), but which nevertheless contributed to their isolation and confinement within their homes:

For teachers you don't belong in the school...so they tell you 'go away'...the mayor tells you 'go back to your home'...and the school children look at you strange...'you are not like us'...all this hurts you inside, and not after long, you are forever locked at home (Oscar)

Protection by parents: participants expressed how when they were younger, their parents sometimes kept them home fearing mocking and taunting by other children, and to prevent them from getting hurt or aggravating their impairments, not irrational considering the state of the roads and the potential for falls. They already lacked the resources to medicate them properly, and hence feared injuries and new costs they couldn't cater for.

Unavailable or erratically available accompanying family members: participants emphasised how negotiating the harsh rural terrain on foot or even by bus (if available at all) necessitates help from family members to be able to get to school. Unfortunately, not all had members available, while others were often too burdened by the dire need to work (lost labour has a high opportunity cost) or were ill themselves, and therefore could not maintain the daily trip:

I only have my father, and if he doesn't work the fields, he doesn't get paid, and if he doesn't, we don't eat...my mother was always too ill to take me (Marta)

Public transport barriers and costs: participants documented deep attitudinal barriers by bus driver who often blatantly refuse to take on disabled people especially those with limited agility to mobilise quickly enough up and down the crowded chicken buses and micro buses, a critical problem that remains as adults. Importantly, the high costs incurred, make transport often inaccessible and expensive, especially for those in more isolated areas. Participants emphasised how for disabled people, these costs double up with an accompanying person.

Inadequate medicalisation, pain and lack or absence of adapted assistive devices: high costs of health care paired with loss of labour mean that health care is often absent or fragmented for poor people (WHO and World Bank, 2011). For participants this meant ill-health, extraordinary unmedicated pain and aggravation of their impairments. Compounded by the lack or absence of affordable and adapted devices such as wheelchairs and prostheses, these barriers translated into limited mobility and ability to reach schools. Critically, they again pitched the pursuit of some pain relief against education, with the latter again being pushed backward as a priority.

Interrupted education and attempts at (re)negotiating barriers

The net result of these barriers as they combined and intensified across a number of dimensions, was frequently the same- interrupted education during childhood. Overall, in the absence of money and escalating poverty, ensuring that the families (including the disabled person) at least ate, became the priority, meaning that families often had to prioritise and choose between education and more basic needs, in particular feeding and medicating the disabled person. This is the point where education was transformed into what one may call a *competing cost*, especially for households with many young mouths to feed, and those with a high dependency ratio.

This education was rarely, if ever to be picked up again in adolescence or adulthood. For those who started performing some or other work (remunerated or not), education then bowed out to the more urgent need to labour, demands that strengthened following the onset of the impairment, and which were felt by all family members, especially when they had to compensate for the disabled family member's lost labour. Only four participants managed to start or continue studying in late adolescence, and only one of these managed to reach post-secondary level with much hardship. These four were all younger participants with no child responsibilities. The findings appear to contradict those by Yeo and Moore (2003) suggesting that disabled people get inferior treatment, have lower expectations placed on them, and overall learn less. For these participants, hurdles indeed appeared to ease over time once they managed to get into school. They explained how after they learnt to negotiate basic infrastructural and architectural hurdles, and teachers and students got to know them and witnessed their resilience, attitudes within the school shifted, translating in turn into greater support. Individual agency, it was clear, can play a determining factor in the treatment they receive by shifting perceptions and stereotypes. Rather than a deficit approach, the findings suggest that the teacher and student developed a relationship, wherein a dialogical process was set in motion leading to a greater understanding of and efforts at removing some of the obstacles (see also hooks, 2003). The lack of alternatives also meant that they attempted to excel at the one shot they had. Continuing a few years of schooling was only made possible after many trials and tribulations because they had no money. Two participants found some financial aid from a small national level DPO, providing the 'bridging social capital' (Woolcock, 2001) by creating connections with the schools, and then covering the expenses of books and transportation. The community and/or family provided critical non-financial support, for example by helping to carry the person to school or to the edge of the road to get the bus. Unfortunately, though, the help from the DPO was only a one-off, and for a designated period. The following story by Alberto highlights many of the barriers outlined above and attempts at their negotiation. Born into extreme poverty and living with polio from the age of 5, he started primary school at the age of 16, overcoming immense obstacles with the help of his family, teachers and community to get his teaching certificate:

... they (parents) told me, 'you are not going to get into school because you are suffering'...I did not have a wheelchair and I was dragging myself on the ground with my arms...with the mud I would get back home wet, my trousers torn...and my parents would tell me 'my heart hurts, you are suffering, I am your body...better if you do not go to school'. I told my teacher and he said 'let's organise groups of students to come and get you', my father said 'ok I will give you a hand' because we had animals and I would ride animals... here (in the village) I did primary then secondary and then the teaching course (Alberto)

Participants stressed that abandoning education was not an easy decision, describing it as 'a painful loss' (Mario) not least because, as highlighted earlier, it has high symbolic value in poor close-knit communities. Participants spoke about numerous reactions by them and their parents to keep their education going for as long as they possibly could, including reductions in food intake, purchasing cheaper (and less nutritious) foods, working harder (including young siblings), and cutting down on other expenses. These included the health care of other family members and transportation. Unfortunately, these responses came at a huge cost, for some compromising even the health of others, and hence could not be sustained over time. They were also not homogeneous, or static. For example in times of drought, food prices shot up, intensifying even further the problems in catering for the costs of education.

Education and poverty: no clear relationship

Participants moved on from the perceived value of education (see above) towards exploring the interactions between education and impoverishment, and it quickly became clear that while a relationship did exist, it was far from linear or straightforward, and can hardly be generalised. Critically, interrupted education appeared to impact poverty in indirect rather than direct ways. Participants highlighted how more education for the poor rarely means better work opportunities, and even less chances of alleviating poverty. Overall, participants expressed substantial reservations about claims that education can 'lift' the poor out of poverty, supporting the notion that rural poverty is more often than not a chronic and intergenerational trap (see CPRC, 2008)- challenging the ease with which 'poverty reduction' discourses and quick fix solutions, including education, are often thrown around:

You are born in it, you die in it, education or not... and noone will do anything about it (Elena)

They emphasised that the poor and marginalised in general confront too many structural, social, political, and other barriers (including racism for indigenous people) to access

education and make it work for them, especially in leading to employment. These have long historical lineages and continue to keep people entrapped as ‘neocolonised bodies’ (Grech, 2012: 52). These barriers are accentuated for disabled people, making the transition from education to work even more difficult for them. Alberto continues talking about his experience of trying to find work with his qualification as a teacher:

... the employers (school) do not give me work, discrimination...I have asked for 4 years, from when I got my certificate... to say it all, even if they employed me, I will not even be able to go through the main door, because there is not one ramp, and like the rest of this place, impossible to move with a wheelchair- a lost battle from the start... (Alberto)

The findings push us to seriously reconsider the ‘human capital’ mantra promoted by parties such as the World Bank, which suggests that education leads to better employment, economic growth, and lifts people out of poverty. As participants stressed, poor people rarely have linkages to powerful others, in particular ‘linking social capital’ (Woolcock, 2001: 13) which could help connect them with potential work or act as employers; they face insidious and chronic unemployment or underemployment; they are often geographically isolated from paying work locations; and like all other poor people, are ontologically invisible other than bodies of cheap and exploitative labour. The low quality public education, they emphasised is also hardly capable of delivering the skills required for the demanding urban job market¹, meeting the consistent neoliberal globalisation that continues to translate into cost-cutting, privatisation and reduced involvement of governments in the welfare of their citizens, including their education. Measures such as these continue to reduce opportunities for public education in the midst of escalating unemployment, poverty and inequality, within an ideological framework where the individualised/self-reliant/productive- non-disabled-body is increasingly valorised. These are the bodies which can translate this education into effective ‘output’- economic growth- with the implication that disabled people are consistently (re)positioned as unproductive, dependent and outside of not antithetical to ‘development’ and perhaps even education - a burden (see Grech, 201; Soldatic, 2011):

The government never bothers about us, gives us nothing, and with a body like mine, you can never make it to give something that it (government) thinks is of any value (Arnoldo)

In Guatemala, ‘quality’ education is only found in private schools, especially those in the capital city. These, combined with social capital, are the portal to work, economic benefits and more social capital, often the privilege of the oligarchy. In turn, the public schools are maintained in deplorable conditions, of low educational value, effectiveness and consistency.

Education in Guatemala is a critical source of social and cultural differentiation, and is one of the many areas where the extraordinary inequalities lived are manifest, and also through which they are created and perpetuated, to use Bourdieu's (1986) words, on account of a 'cultural capital' that maintains class divisions. As Álvarez Aragón (2005:116) emphasises, in Guatemala 'school by itself does not break inequality, but rather the other way round: it helps reinforce it' (see also Giroux, 1998).

The fact that education provided no assurance that it would translate into work over the short and medium term, affected numerous decisions around education, including whether it was considered at all, and how much families were willing to invest in it, and for how long. As young and older adults, the costs of education did not only include money, but also time required to seek out information, and time away from livelihoods and other productive activities, all of which have not only monetary value, but are critically linked to personhood and satisfy social expectations. Decisions on education, in particular hinged on its perceived and actual contributions to immediate family welfare and survival, most basically food and some or other erratic health care, suggesting that 'practical' needs almost invariably dominate 'strategic' ones (see Molyneux, 2003). This is perhaps not illogical when education is ultimately a long term strategy, providing no immediate solution to the satisfaction of immediate needs such as hunger. And when one does not have money to put food on the table today, any long term future plan becomes superfluous:

You farm, you get money, you eat... you don't farm, you and your children starve
(Felipe)

The perceived value of education in relation to its potential contribution to the whole family, also appears to contradict the European and North American emphasis on individual growth and attainment. The individual right to an education is therefore subsumed under the collective (perceived) right to co-exist where family benefits are shared.

But while participants were reluctant to overstate the potential of education as a means of pulling them out of poverty, they nevertheless did feel that lack of education contributed to maintaining their poverty. Unlike other studies (see for example Filmer, 2005), lack of education appeared to be a dynamic of impoverishment for disabled people, not because it reduced work possibilities or the chance of earning higher incomes. Indeed, apart from the numerous obstacles to paid employment, most of the work performed by the rural poor is unskilled and often precludes some disabled people on account of its strenuous nature (e.g. construction work). These are also contexts where choices of alternative paid work are either scarce or absent. On the other hand, barriers to education appeared to impoverish indirectly by propagating and/or normalising even further the invisibility of disabled people from public spaces, an invisibility that is often as physical as it is ontological. Participants recounted how

this invisibility meant reduced opportunities to build friendships and networks of support and to find and maintain contacts for work. This is critical in rural contexts where life and access to assets are organised around family and community participation. It also weakened the spaces for personal and social validation, and shrunk the support needed to negotiate the psycho-emotional aspects (Reeve, 2002) related to the onset of their impairment, and the disablement and shifts in poverty they experienced:

We live in communities here, and schools are communities too... to show what you are capable of doing so they get to know you, and you make friends who then help you and your family through difficult times like when you have an illness...some discriminate you... and you lose everything and you become poorer because you can no longer work (Evelyn)

Conclusions and Discussion

This paper has mapped out complex and interacting barriers to education in poor rural areas. The fact that many of the barriers are a generalised reality for poor people, places the understanding of poverty at the forefront of the analysis on educational barriers as opposed to looking at disability in a decontextualised and isolated way. The findings point to the need to learn about what Grech (2014) calls the *spaces of poverty*, the socio-spatial, economic, political and historical aspects of these poverty contexts without undermining their complexity, heterogeneity and dynamic nature. These form part of a composite and heterogeneous global South (from local to global) that is the repository of anxieties, tensions, conflicts, ambivalences, geopolitical asymmetries as well as resistance.

Decisions around education are clearly linked to perceived material output, or rather if it will contribute to the household economy and family welfare in the short term. Even where certificates are attained, as was the case for Alberto, employment is still often blocked—formal education provides a certificate, but stops short of transforming the disabling structures grounded in social, political, economic, ideological, gendered, racial and other dimensions faced by the poor. For the indigenous population, these are intensified racially and also linguistically, where language remains a dialectic connecting power/knowledge (Foucault, 1980). These barriers can only be understood historically and discourses and ‘solutions’ can only be framed in relation to and within historical confines and possibilities. Education within a context such as Guatemala importantly needs to be examined and addressed as a mechanism that contributes to sustaining deep inequalities that are themselves historical.

The findings presented in this paper suggest that more education in practice, rarely means better work opportunities, and even less chances of lifting out of poverty. The suggestion that

education is played out on a level playing field and automatically leads to better social and economic prospects, remains hugely contestable in contexts wherein the rural poor continue to confront fragmented livelihoods, and where chances of paid labour remain scarce in spaces where poverty is chronic, intergenerational and the present survival is the critical preoccupation. The findings are clear in stressing that for those in extreme poverty, practical and immediate needs dominate over more strategic, and hence longer term ones, influencing decisions, expectations and resources invested. Dropping education within this context is not unreasonable, especially when it fails to provide immediate returns on their investment, in particular the expenses incurred. At a more conceptual level, this situation warrants against discourse demonising the poor as people who do not want to educate themselves or their children. It is not only a question of household economics. It is also a question that when practical needs dominate, practical outcomes are the priority, and these outcomes come with a short time lag expectation. Investing in education in the hypothetical scenario that it may help with hypothetical employment opportunities in a hypothetical future that may not come is not of much use to the poor whose existence is dominated by a survival imbued with immediacy. Neither is the discourse around education for personal growth of much value, when these epistemological, existential and psychological arguments are fractured by more material hunger and ill-health. To restate, any understanding of education within these poverty contexts and decisions and choices around it, cannot possibly remain detached from solid understandings of the complex 'habitus' (Bourdieu and Passeron 1977) of the poor shaped by interactions between structures, histories, contexts, and personal experiences and perceptions.

It is also clear from the study that national policies and international declarations (including the UNCRPD) and discourse around 'inclusive education' and rights mean little in practice when in rural areas: these are hardly known by teachers, schools and even disabled people and their families; schools are not obliged to make any adjustments and have no resources for training and materials; and there is no monitoring and enforcement of policies. Importantly, when people are primarily preoccupied with the fight for daily survival, rights and policies on paper will forever remain confined to utopian rhetoric (Grech, 2009). Promoting education for the poor as well as for disabled children cannot possibly ignore politics (national and local level), and how these interact with, shape and even resist policies and their implementation. And this needs to be framed within real, rural poverty spaces, the limitations they impose, and the way these can even be capitalised by politicians and others to maintain the status quo or to exclude disabled children. When there is poor infrastructure in schools, low quality education and over-crowdedness, and when schools are stretched beyond capacity, unable to address the educational needs of the children that they do have, disabled children will be forever positioned as a burden and 'out of place'. In the absence of investment in resources and training of staff in mainstream facilities, special schools may indeed remain the only option, and may need to be stepped up, when this may be the only form of quality education possible, at least until mainstream schools can really accommodate them. At the very least,

overzealous enthusiasm about imported inclusive education discourse and the demonising of special education by disability and other activists can do little, and even be harmful when disabled children in extreme poverty, remain barred from any schooling, where policies are simply slips of paper, the poor cannot afford to seek redress, and when the extreme poverty they inhabit remains ontologically distant and unfamiliar to the urban elites and their associations promoting this discourse in the first place. This is a critical concern within neoliberal spaces persistently reframing these poor as abject subjects whether by politicians or the oligarchies, translating into perpetual marginality, social exclusion and injustice (Tyler, 2013).

Efforts at enhancing access to education in contexts of rural poverty need to be multi-sectoral and address the needs of whole families, impacted by disability or rather *disabled families*. It is only when families are more resilient and food-secure that education will not hinder the achievement of other basic needs such as health care, and importantly can be maintained over time. Research is needed on the interactions between educational barriers and access to these other basic needs, calling for consistent attention to what López and Tedesco (2002, cited in Tarabini-Castellani Clemente, 2007) call ‘educability’ that is how socio-familial roles impact and interact with education. But more research is also needed looking at the educational needs and barriers confronted by family members across space and time. Measures need to be in place so that the education of the disabled person does not compromise consumption by and well-being of other family members, including of their own health and education. Material support is also needed to facilitate the education of children of disabled people. Support with these costs ultimately impacts the well-being of the disabled parent, for example through more resources for his/her health care and food, without compromising opportunities, including education.

Finally, the findings are clear also in suggesting that initiatives cannot be limited to disability-specific ones e.g. disability quotas in schools. Instead, efforts addressing the learning and other needs of *all* rural poor are urgently needed through a participatory pedagogy affirming collective knowledge, grounded in their experiences, building on strengths, and offering the possibility for real transformative change within context (see Foley, 2004). Indeed, ‘inclusive education’ will perhaps remain an oxymoron when education is not even inclusive of the poor in the first place. An education that is contextually relevant, and recognises, affirms and responds to the needs of children, families and communities in rural poverty, and which importantly helps foster skills and create opportunities for paid labour is urgently needed (see Mayo, 2005; Lipman, 2009). Disability-specific initiatives should serve to strengthen these measures rather than replace them. Disabled students also need help with the costs of attending school, including transportation (for them and any accompanying family member), and compensation for any loss of income incurred by those accompanying them.

Notes

¹Guatemala, like many other countries, has signed most of the above conventions, declarations and international treaties, including the Inter-American Convention on the Elimination of all forms of Discrimination against Persons with Disabilities (1999- ratified 2003); ratified the Protocol of San Salvador; and ratified the UN Convention on the Rights of Persons with Disabilities in 2009. Disability and education also feature in a number of national level policies, declarations and the constitution including: the National Disability Policy in 2006; the Law of Integral Protection of Children and Youth (Decree-27-2003); the Law on National Education (Decree 12-91); the Social Development Law (Decree 42-2001), the Governmental Accord on the creation of the Department for Special Education (156-95), and the Policy and Legislation on Access and Education for the Population with Special Educational Needs (830-2003).

² Even the Global Monitoring Report (World Bank, 2008) recently warned, that increased access to schooling is not translating into substantial benefits such as preparedness for work on account of the low quality of education and inequitable access among others, and which in turn threaten the achievement of MDG 2 (providing universal education by 2015).

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