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Situational analysis of poverty and violence among children and youth with disabilities in the Americas – an agenda proposal

Análise da situação da pobreza e da violência entre crianças e jovens com deficiência nas Américas – uma proposta de agenda

Fátima Gonçalves Cavalcante ¹
Edward Goldson ²

Abstract *This article reviews the prevalence of poverty in Latin America and the Caribbean discussing the cycle and culture of poverty; their links to violence and maltreatment among disabled children and youth, from 1990 to 2006. There is a discussion of child maltreatment both of typical and disabled children taking into consideration the disabled child's unique needs, the impact on the family and society and the availability of supports and resources. Finally, an agenda is set forth to address poverty and violence, seeking to diminish the prevalence of maltreatment of all children, but especially children with disabilities. In addition, there is the hope of breaking the cycle of poverty and supporting disabled and marginalized individuals. This agenda speaks to the need for multidisciplinary collaboration as well as collaboration regionally and locally among governmental and non-governmental agencies, advocacy groups and the community at large.*

Key words *Poverty, Disability, Maltreatment among children, Political agenda, Cycle of poverty, Culture of poverty*

Resumo *Esse artigo revisa a prevalência da pobreza na América Latina e no Caribe, discute o ciclo e a cultura da pobreza e sua interface com a violência e os maus tratos contra crianças e jovens com deficiência, de 1990 a 2006. A discussão sobre os maus tratos focaliza crianças com e sem deficiência, levando em consideração a especificidade e necessidades singulares das crianças com deficiência, o impacto na família e na sociedade e a disponibilidade de suporte e recursos. Finalmente, uma agenda é proposta para abordar o tema da pobreza e violência, ao procurar diminuir a prevalência de maus tratos entre todas as crianças, especialmente as crianças com deficiência, ao quebrar o ciclo de pobreza e dar suporte para indivíduos com deficiência e marginalizados. Essa agenda aponta a necessidade de colaboração multidisciplinar, como também colaboração regional e local entre organizações governamentais e não-governamentais, grupos de auto-ajuda e a comunidade mais ampla.*

Palavras-chave *Pobreza, deficiência, Maus-tratos contra crianças, Agenda política, Ciclo da pobreza, Cultura da pobreza*

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Introduction

The goal of this paper is to provide visibility to a triad of problems: poverty, disability and violence. These issues, when treated separately have not had the same impact on the public and among government officials and scientists as when considered together. The eradication of poverty is a millennium world goal which, in order to be achieved, depends on cooperation and exchange between nations, governments and international monetary funds. This paper will address these issues with a focus on the Americas, especially Latin American and the Caribbean. It is necessary to shed light on what seems to be an invisible problem: disabled people are the poorest of the poor and will remain at risk for increasing poverty, worse impairments and mental disorders and domestic or institutional violence, unless public policies, governmental and non-governmental agencies, advocacy groups, families and people with disabilities, empowered and better organized, do something. In this paper we are going to describe what has been recently done in the Americas about this triad of issues and what should be the agenda for the disability and mental health fields in order to better prevent poverty, disability and violence.

It is a privilege to introduce the issue 'poverty, disability and violence' in this article-debate with colleagues from the Americas, specially, United States, Colombia and Brazil. This international exchange is important for two reasons: (1) All people engaged in the article and in its debate, participated in the International Seminar: "*Perspectives of facing the impacts of violence on public health: Latin America in focus*" organized by Fiocruz Foundation/Ensp/Claves in Rio de Janeiro, Brazil in November, 2007; (2) This paper gave the authors the opportunity to share their efforts and studies, first by combining their accumulated experience acquired in practice and research in the disability field. Second, it provided the authors a way to present studies on maltreatment starting with the one written by Denver pediatrician C. Henry Kempe and his colleagues¹, concerning the battered child syndrome (1962), and including the ones from this decade². Third, it provided the authors the opportunity to present the work developed with colleagues on the first Brazilian qualitative research^{3,4} addressing the combined issue of violence, disability and poverty (supported with grants from CNPq/MS/DECIT and FAPERJ 2005-2007). This work seeks to enhance human rights protection and violence prevention among children and youth with and without disabilities.

Poverty and inequality in Latin America and Caribbean

According to data⁵ gathered during the 1990s Latin America and the Caribbean (LAC) reduced poverty. Although the reduction was not uniform across countries (in a sample of 17 countries, 6 of them had poverty increased) the incidence of poverty decreased over 10 percent. However, the absolute number of poor people increased during the decade due to population growth. One third of the 180 to 220 million people in LAC, live in poverty according to data collected in 1995⁵ and in 2002⁶. Most of them earn less than two dollars a day. Poverty is concentrated in households whose heads are employed in agriculture (35.5 percent) in rural areas, or in nonfinancial services (29.1 percent) in urban areas. Almost 44 percent of all children (0 to 17), compared to 27.7 percent for adults and 28.6 percent for elderly live in poor households. In urban settings poverty is higher among female heads of household (30.4 percent) than among their male counterparts (25 percent). Also, gender, ethnic and racial origins are also a feature of LAC poverty. In Bolivia, Brazil, Guatemala and Peru the incidence of poverty is twice as high for indigenous and afro-descendants, as compared to those of European descent⁵.

Studies of aggregate poverty and inequality estimates in LAC during 1970-1995^{7,8} agreed with the description that poverty and inequality were reduced during the 1970s, according to welfare changes at the microeconomic level. These indicators deteriorated sharply during the 1980s, with different phases of growth or recession in each country. Given the favorable conditions observed in the first half of the 1990s, it was expected there would be a reduction in the number of poor and the level of inequality. Even though the 1990s was a decade of recovery and stability, poverty and inequality have not declined significantly in the region^{7,8}. The gains in social indicators observed at the end of the decade were a modest reduction in poverty with progress in primary education and gender equity in school enrollments. However, there was less progress in reducing infant mortality, expanding the potable water supply, and controlling HIV/AIDS and other infectious diseases. It is important to note that progress has not been uniform across all countries in the region, since high achieving countries experienced reduction in infant mortality rates and have immunization rates of almost 100 percent⁵.

Disparities in human capital, social conditions and living standards between regions within coun-

tries make LAC the most inequitable in the world^{5,7-9}. In the late 1990s, the wealthiest 20 percent of the population received 60 percent of the income, while the poorest 20 percent received only 3 percent. The gap between the poorest and richest segments of the population has widened in the past three decades^{5,7}. In most countries inequality is higher than expected according to per capita income. Inequalities are also associated with huge inequities in the distribution of resources like education, health, land and credit. Children of the poor have more disadvantages (higher child mortality rates, greater school dropout rates, higher youth unemployment) than children of the wealthy. In Brazil, for instance, by 18 years of age only 15.2 percent of children among the wealthy had developmental problems while these problems occurred in 64.3 percent of poor children⁵.

Social exclusion is another problem, which is both a cause and effect of inequality. Socially excluded populations from LAC differed by gender, age, race, ethnicity, immigration status, HIV/AIDS, mental health disorders and disabilities. They share poverty, suffer multiple and cumulative disadvantages, stigma and discrimination. Persistent educational gaps between rich and poor are the key in explaining income inequality^{5,7-9}. The schooling completion rates are 4 years for the poorest 20 percent and 10 years for the richest 20 percent⁵. Differences in the number of school years significantly affect income. Those with a primary school education have an income 18 percent higher than those having no schooling. A secondary school education yields returns of 61 percent and higher education yields returns of 152 percent¹⁰. The poor distribution of health, physical capital, including land, credit and infrastructure (energy, water and transportation), lack of employment opportunity, informal services are combined factors related to social exclusion and inequality. The authors^{5,6-9,11} concluded that the lack of progress in poverty reduction in the 1990s is due to the persistently high levels of inequality of education leading to economic and social disadvantages.

Considering that poverty and inequality are the most important problems to be faced in the world nowadays, in 1996 the United Nations Development Programme (UNDP) started a global initiative to assist poor governments in organizing national and local Poverty Reduction Strategies (PRSs). In 1999 this step was followed by the International Monetary Fund (IMF) and the World Bank. In the LAC region, the Inter-American Development Bank joined IMF, World Bank and other agencies in supporting regional countries. The PRSs

serve to identify priorities, to elaborate policy reforms and key strategies for long-term poverty reduction goals, using indicators to measure their progress. Four Latin American countries are participating and have completed PRSs: Bolivia, Guyana, Honduras and Nicaragua. Some countries of the region have implemented other types of integrated approaches for poverty reduction: Brazil, Mexico and Chile created new instruments to face poverty. Brazil and Mexico are addressing individuals at all stages of the life cycle: prenatal, infancy, adolescence and youth, adulthood and old age. Chile's program combines assistance and the effort to empower and bring social integration to families living in extreme poverty in four areas: income (jobs), human capital (education, health, training and housing), social capital (social network) and vulnerability (by prevention). LAC countries and international agencies are using multiple fronts to face poverty and inequality^{5,9}. According to Bouillon & Buvinic⁵ ***investments in the human capital of the poor should be a chief priority in the policy agenda and in the allocation of public resources, and should be promoted through reforms that increase quality and coverage of basic social services.***

Poverty and disability in the world

According to the report *Understanding Inclusion* of the First Inter-American Forum on Poverty and Disability in the Americas that took place in Managua, Nicaragua in August, 2004 (with 13 countries from LAC)¹², the links between poverty and disability – that poverty causes disability and disability causes poverty –, has not yet been addressed. One of the barriers to addressing this issue is related to definitions of poverty. The way one thinks about poverty affects what one measures, and what one tries to change. Instead of thinking of poverty only from a monetary perspective, newer definitions focus on capability, social exclusion and participatory behavior^{6,11-15}.

Poverty is a multidimensional phenomenon related to the lack of material supplies and varying inequalities, each one coming together, influencing each other through inequities in school completion, access to health care and employment, among others^{6,14}. Instead of thinking of poverty only as lines of poverty, Costa & Carneiro¹⁴ suggested one consider the different dimensions of poverty. In other words, consider multiple privations, including non-material privations, especially in chronic poverty. One should consider the attitudes, values, behav-

iors among the very poor and the limits of their capability in the use of public resources and services. The authors¹⁴ use the term privation of capabilities as a way of linking poverty to social exclusion, both being described as the reflection of several vulnerabilities, which have to be seen more as a process, than as a stable condition. So, in considering strategies to reduce poverty it is necessary to consider the relationship between a number of variables: the dimensions of education, health, the nature of the household and income. Since exclusion is related to distinct situations, poverty reduction programs should be flexible, should strive for empowerment and social networking. In order to accomplish these tasks efforts from international and national financial agencies, governmental and non-governmental organizations, private and public institutions, families, communities and representative groups need to be coordinated. Only with societal efforts and commitments, especially with the participation of poor people, who understand and appreciate more clearly their day-to-day problem, will it be possible to face the major problem of the millennium: poverty.

In 2000 the United Nations adopted the Millennium Development Goals to consolidate efforts to reduce poverty in the World. These goals include:

1. Eradicate extreme poverty and hunger; 2. Achieve universal primary education; 3. Promote gender equality and empower woman; 4. Reduce child mortality; 5. Improve maternal health; 6. Combat HIV/AIDS, malaria and other diseases; 7. Ensure environmental sustainability; 8. Develop a global partnership for development¹⁵.

In both wealthy and poor countries, people with disability and their families pay an economic, social and political price. Excluded from education, they have less opportunity to earn a decent living, mothers or caretakers have to sacrifice work or education. In addition, there is the extra cost of medicine, health care, special diet, and adapted transportation. Families are marginalized, isolated and stigmatized. There is a lack of time and energy to build social networks or to engage in political activities, and little opportunity to influence the policies that affect them. Why are people with disability and mental health care needs the poorest of the poor? The answer is simple: there has been no attempt or an investment of political will to translate their legal rights under the law into reality. As long as the design of poverty reduction strategies is still related to traditional economic measures, as the criteria to allocate resources, than people with disabilities, and their families, will remain among the poorest of the poor¹².

According to Wolfensohn¹³ until recently disabled persons were nearly “invisible” in Poverty Reduction Strategy Papers (PRSPs). In 2003, the issue of disability became more prominent, especially among Eastern European Countries. The author¹³ reviewed a total of 33 PRSPs, selected from 2000 to 2004. His purpose was to review the disability policy content of PRSPs. The PRSPs were introduced in late 1999 as a key instrument for Heavily Indebted Poor Countries (HIPC). Since then, 38 PRSPs have been prepared, most are found in Africa (twenty), others in Asia, seven in Eastern Europe and four in Latin America. This study concluded that 73 percent of PRSPs recognized that disabled people live in the poorest households and are at risk for experiencing significant poverty. However, few PRSPs described the poverty risks faced by disabled persons and the mechanism exclusions. Only 23 percent mentioned the exclusion and stigma faced by disabled persons, but even in these cases there is no recognition of the cumulative nature of disabilities. Strong emphasis was given to early childhood interventions (90 percent of PRSPs), but only a minority included specific rehabilitation measures (43 percent) and there is a lack of attention given to mental health disorders, alcohol and drug use.

The size of the disabled population remains a controversy, depending on the definitions of disabilities. Some countries' population census suggested 2 to 3 percent of population suffer from most extreme forms of disabilities. Other countries with broader definitions of disabilities have reported a much higher rate of disability, 15 to 20 percent of the population^{12,13}. According to the World Health Organization¹⁶, disabled people account for 10 percent of the population worldwide.

The impact of poverty on quality of life

Disabled people are affected by discrimination, social exclusion and stigma. If left unaddressed, the cumulative effect of these experiences translates over time into a combination of exclusions that result in social disabilities and poverty. To comprehend the impact of poverty on life, we need to answer two questions: How do initial impairments results in social disabilities and poverty later on in life? What does it mean to live in the dual realm of poverty and disability?

A World Bank study revealed that half a billion disabled people are among the poorest of the poor¹⁷ and are estimated to be 15 to 20% of the poorest in developing countries¹⁸. According to UNICEF, less than 3 percent of disabled children are enrolled in schools and most disabled adults are excluded

from productive employment¹³. Although in the countries of the LAC there are limited statistics about the impact of poverty and disability, data from governments, international agencies and non-governmental organizations¹² point out that poverty and disability influence each other and often co-occur.

Since it is observed^{17,18} and expected¹² that there is a high rate of chronic poverty among disabled people, it is important to point out that not all disabled people are poor, in economic terms. However, under conditions of chronic poverty, social exclusion is a major issue, due to lower expectations, lack of resources, poor health and poor education. Social exclusion, more than poverty, is experienced in a broader way for most disabled people, due to the vulnerability related to social status, stigma, privilege, race and gender.

Many disabled children do not survive, particularly those born in poor communities. The ones who survive grow up excluded from formal and informal education, which affects their ability to earn a living, and their level of confidence and self-esteem. The consequence is that later they will have restricted employment opportunities due to inadequate or a lack of an education, discrimination, isolation, a lack of experience and confidence. Excluded from social, economic and political opportunities, disabled people fall further into chronic poverty and have little opportunity to break the cycle of disability-poverty (Figure 1). On the other hand, severe poverty increases the risk of being impaired. Life in chronic poverty limits the access to land, shelter, healthy food, healthcare, education, employment, and offers hazardous working conditions¹⁹. These cumulative factors can cause illness and impairments, leading to more marginalization and exclusion, resulting in disability that emerges as a cycle of poverty-disability (Figure 1).

A strong emphasis on quality of life of people with disabilities has been prevalent over the past two decades²⁰⁻²². This concept emerged as a useful indicator of outcomes of policy initiatives²³. According to Park, Turnbull & Turnbull III²⁰ quality of life experienced at the family level can be defined as the way family members have their needs met, enjoy their life together as a family and have opportunities to pursue and achieve goals that are meaningful to them. The authors pointed out, as an international agreement among research teams, that there is no standard family quality of life and each family decides what "quality" means to them. Between the tension of 'social parameters' for policies and 'family's life perception', the authors proposed five domains with which to examine the impact of poverty

on family quality of life: physical environment, health, emotional wellbeing, productivity and family interaction. We included education among the others, as you can see in Figure 2.

The six domains are defined as: (1) Impacts on physical environment – home environment and neighborhood environment which include land, shelter, infrastructure (energy, water, transportation, housing supplies) and social network within the community; (2) Impacts on health – family's health status, health care and health impact, especially related to hunger, under-nutrition during pregnancy and limited access to health care; (3) Impacts on emotional well-being – the emotional aspects of family quality of life related to stress and adaptability (feelings, anxiety, mental health problems and coping strategies); and self-esteem (the degree to which the individual evaluates his or her own worth); (4) Impacts on education – cognitive development and schooling, social and life skills, academic and language stimulation, extra-curricular activities (sport, arts, leisure and recreation, cultural events); (5) Impacts on productivity – useful activity which helps to develop working skills, training of specific competences, participation in meaningful social and cultural activities, jobs opportunities, personal accomplishments; (6) Impacts of family interaction – conscious and unconscious components of family life, routines, relationship among family members, roles, emotional climate, communication, behavior and forms of discipline, with special focus to the parent-child interaction (sense of security and trust) and other family interactions (the way they lead to pressure, conflicts, frustration, gain satisfaction, enhance adaptability to the member with a disability).

Since poverty permeates several domains of a family's quality of life no single profession or agency can meet the multifaceted needs of poor children and their families alone²⁰. It is necessary to establish school-family-community partnerships as we will detail later. A third factor associated with chronic poverty and disability is going to be presented now, by addressing the link between disability and violence.

Violence against disabled children in the Americas

One of the characteristics of the 20th and 21st centuries has been the persistence of violence among nations and individuals. It is clear that violence, in all of its forms, is destructive to human life and to the well-being of mankind. Moreover, it is most

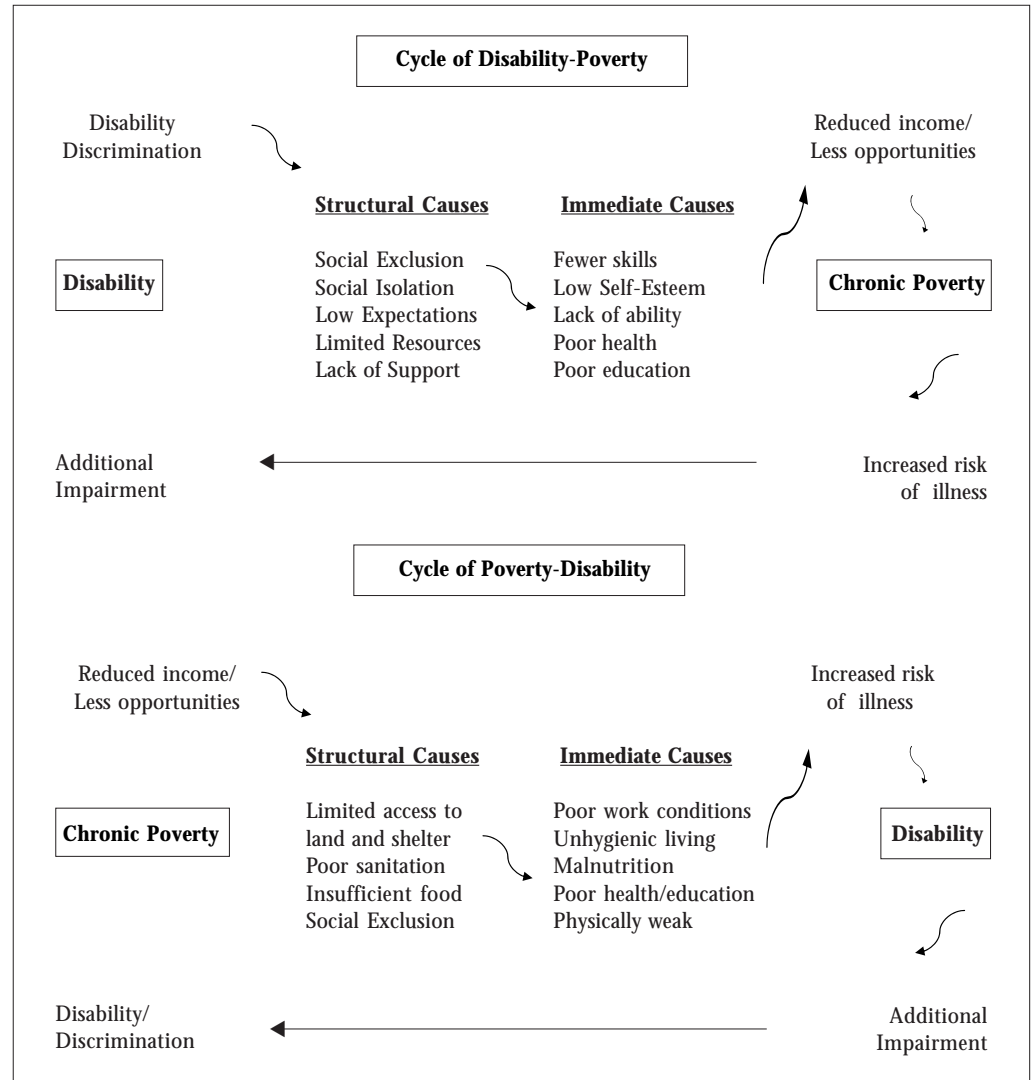


Figure 1. Cycle of disability-poverty.

Source: Richler¹², Wolfensohn¹³, Yeo¹⁹.

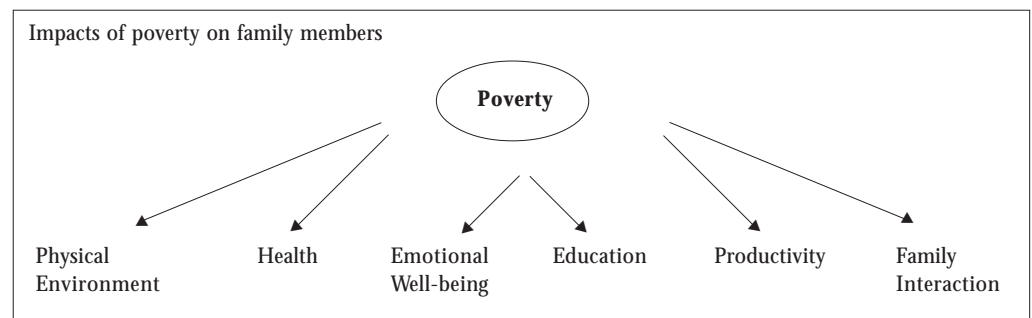


Figure 2. Impacts of poverty on family members.

Source: Park, Turnbull, Turnbull III²⁰.

destructive to those members of society who are dependent on the support of those responsible for their care, love, guidance and protection, namely children and youth and, more specifically, individuals with disabilities or special health care needs. Considering a more focal and local perspective, violence has been an integral and dominant factor in the history and political and social life of Latin America which, unfortunately, continues to be so. Latin America is one of the most violent regions of the world. Interpersonal violence was the fifth most important cause of death in the total population in LAC in 2002⁶.

Maltreatment of children is widespread around the world and has been so for generations. As one attempts to address the issue of maltreatment it is important to have clear definitions of this phenomenon. Below are cited two definitions (or descriptions) from the United States: (a) ***Child maltreatment means the physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a child by a person who is responsible for the child's welfare under circumstances which indicate harm or threatened harm to the child's health or welfare***⁴; (b) Child maltreatment means "Any interaction or lack of interaction between a child and his or her caregiver which results in non-accidental harm to the child's physical or developmental state"²⁵.

The first definition is a legal one and is embodied in the United States Code. The second definition is a pediatric definition. These definitions are different in origin, yet very similar in content despite the differences in the wording. The legal definition forms part of the foundation for all reporting acts in the United States, which are part of the laws in all 50 states in union. The pediatric definition by Dr. Ray Helfer, articulates the relationship or lack of relationship that can be destructive to the child's physical and developmental well-being. At the same time, it should be noted that "child maltreatment" is an umbrella term under which are subsumed several subtypes of maltreatment including non-accidental trauma, neglect, sexual abuse, physical and psychological abuse.

In the United States, as reported through the National Center on Child Abuse and Neglect (NCAND) in 2004, there were 1,860,070 reports of suspected abuse from 49 states and the District of Columbia. From this group 477,755, which represents 25.7% of the initial reports, were substantiated through legal processes²⁶. In reviewing the percentage of each form of abuse, 62.4% involved neglect, 2.1% involved medical neglect, 17.5% were the result of physical abuse, 9.7% of the children were sexually abused, 7% experienced emotional

or psychological abuse and 14.5% involved some other form of abuse such as abandonment. Although, it is frequently otherwise believed, child maltreatment is a family affair, which involves all social, ethnic, racial and socioeconomic groups. The most frequent perpetrators (78.5%) are parents with an additional 6.5% being other relatives and 4.1% unmarried partners. The remainder of the perpetrators is foster parents, day care providers and others. By and large, children are not abused by strangers. One thousand four and ninety of these children died as a result of their abuse in 2004.

The more specific focus of this paper is violence and maltreatment among children with developmental disabilities (DD). Children with disabilities are a subgroup of the population of children with special health care needs (CSHCN). This group is of importance in that it represents a significant population of children in the United States. It is defined as follows: "children who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally"²⁷. This then defines the overall population of children to be addressed in this paper. Finally, there are data concerning the incidence of maltreatment among children with disability (a subset of CSHCN) reported by NCAND in 2004. With respect to this population the data are incomplete but 36 states reported 559,410 victims of maltreatment. Of this number 41,083 (7.3%) had a disability. This suggests that this is a population at increased risk for being maltreated. This reflects the state in the United States.

In LAC, we have data on childhood mortality. In Costa Rica, there is a death rate of 13.7 children per thousand before one year of age. In Haiti, the rate is 86.2/1000, in Bolivia to 75.1, in Brazil to 57.7 and in Peru to 55.5. Unfortunately, this public health indicator has not decreased in LAC, as expected during the 1990s⁹. Several indicators reveal a process of family weakness. There is an increase in the number of families with women heads of household, poor and alone (more than 20 percent). Between 30 to 50 percent of women suffer psychological violence at home, and 10 to 35 percent suffer physical abuse²⁸. In the region there are more than 17 million children who work, according to International Work Organization⁹. It is observed as well that there is a growth in juvenile delinquency and in the number of street children²⁹. Unfortunately, there are very limited, if any, data gathered in a reliable and organized manner documenting specifically maltreatment among children with disabilities em-

anating from LAC or countries like Brazil, Bolivia among others. Reporting systems designed to identify abuse and protect the victims are poorly organized. It is necessary to confront the lack of information on the issues of poverty, disability and maltreatment by establishing a better system of information gathering which should be one priority of a public agenda, thereby addressing this problem directly and making it more visible.

Child, family and society

One of the central issues that need to be addressed is why are children with disabilities seemingly so vulnerable to abuse? This is the case in the United States and seems to be so in Brazil, Colombia, Peru and other countries from LAC. One way of framing the question is to look at the three participants, or stake-holders: the child, family and society and think of them as forming a ven diagram. Each brings a unique constellation of characteristics, challenges, needs and expectations that interact with one another and can lead to maltreatment, or possibly to more positive relationships and outcomes.

Let us consider the child with a disability first. By way of generalizing one can accept that many children with disabilities have significant behavioral problems that are difficult to manage, are manifested under circumstances that are challenging and/or embarrassing for the caretaker (i.e. acting out in public or having school difficulties) and create considerable distress and embarrassment for the family. In addition, children with developmental disabilities (DD) frequently do not meet their parents' expectations, particularly those who appear "typical" but do not behave in a typical or acceptable manner. This creates tension, stress, frustration and anger among caretakers. For children with DD with more complex medical and physical problems their care is physically demanding, time-consuming and costly. These children are irritable, their care is unrelenting, they do not recover or 'get well,' respite care is frequently unavailable which places enormous stress on the entire family including siblings. In addition, both in the United States and LAC, there are limited resources for care and education of these children which, even when they are available, are very costly and otherwise frequently difficult to access leaving the family with limited supports and guidance. Fatigue, frustration, financial and emotional stress, unrelenting care, no respite and limited resources and poverty are the conditions under which many families with children with DD live. Parents "burn out!"

The second component of the diagram is the caretakers, usually the parents. Frequently, as a result of the disability and the family's response to the disability, they become socially isolated, rejected and marginalized. Unless they can become involved with other parents with children with DD who can provide support, their lives are constrained and limited. These conditions interface with family dysfunction, not infrequently associated with caretaker immaturity and limited access to formal and informal supports. Furthermore, caretakers of children with DD may have their own psychopathology, which compromises their ability to be effective caretakers. What often also takes place is parental denial of the disability leading to poor utilization of resources even if they are available. In addition, the establishment and maintenance of a parent-child relationship that is nurturing and interactive is compromised and often disrupted. Finally, and of great significance, is parental sense of guilt, inadequacy, a sense of having no control and being overwhelmed by the multiple demands placed on them by the child and his/her needs, inadequate financial resources inadequate services and unresponsive systems.

The third component of the diagram is the community/society. First, I would suggest that United States, like LAC culture, values "self-reliance," an able body and a "can do" attitude. By and large these societies take a dim view of individuals who are "different" and not in the mainstream. The vulnerability of disabled children stems from their experience of having disabilities in a society which puts value on being non-disabled ("able-bodied") and which discriminates against disabled people³⁰. In addition, both the United States and LAC are violent societies. We live in cultures that allow and encourage the use of violence to resolve conflict, deal with frustration and stress and address differences and unmet expectations. We tend not to use mediation and non-violence to address these issues, which are frequently associated with disability and made more complex by the presence of poverty and inadequate systems and supports.

It is also of significance that society has many misconceptions of the disabled and some distinct prejudices. There is the belief that the disabled do not feel pain like typical individuals. The disabled do not have the same needs and feelings and desires and the capacity to be loved and to love as do non-disabled individuals. As a result of the "less than human condition" they are not entitled to the same rights and consideration as are able-bodied children. Resnick in a 1984 paper articulates these perceptions, some of which may have changed in the

last 24 years, but I would hazard to say still persist. In a study of professional staff views of individuals with disabilities he noted a hierarchy of acceptability. The least acceptable were those individuals with mental retardation, syndromes and cerebral palsy. Medium acceptability were those individuals with blindness, deafness, speech deficits, seizures, and by implication those with learning disabilities and psychiatric disorders. The most acceptable among the disabled were those with amputations, those who were wheel-chair bound, those with chronic illnesses but all of whom were intellectually competent³¹. Resnick also described the "sociological destiny for the disabled" which included lower educational attainment, a greater incidence of non-employment and lower wages when they are employed, a lack of upward mobility resulting in poverty. In addition, the disabled tend to be more socially isolated and have fewer social contact, have more medical problems and "they don't get well"³¹. Finally, by way of summary Resnick states, *To be a help person in this cultures which values self-reliance and independence, includes subtle yet pervasive expectations in terms of dependency and gratitude. The ramifications of such a social identity are enormous*³¹ (Figure 3).

One of the questions that emerges, as one considers maltreatment among the DD population, is whether there are particular groups that are more

vulnerable than others. In the past, sexual abuse was reported more commonly among institutionalized individuals³². One sense is that this has changed as many institutions have closed in the United States. This is also the case in Brazil as an example of the effect of the deinstitutionalization process, especially in mental health field related to the Brazilian Psychiatry Reform within the last two decades. It should be noted however, that from the accumulated data that it is not necessarily the most profoundly disabled but rather those who may be higher functioning, who have significant behavioral problems and who do not meet their caretaker's expectation (parents, teachers) who are at greatest risk for maltreatment.

Finally, among the key issues for children with disabilities is the prevention of maltreatment. This needs to take place within existing cultural contexts, which will not be altered immediately although strategies for change should be considered. One could argue that early identification of impairment and disability would be critical in preventing maltreatment as one would hope these children and their families would be directed toward systems and programs designed to support, educate, and nurture. These programs could be established and/or expanded even within an environment conducive to violence.

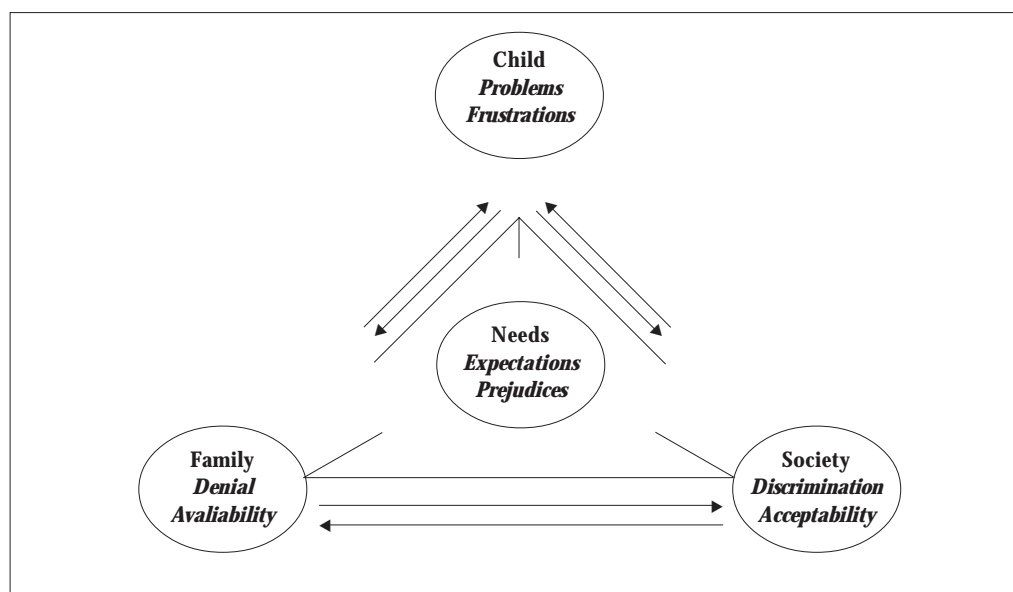


Figure 3. Child disability development within family and society.

Poverty, disability and violence

It is important that we recognize that not all disabled people are poor, and that not all poor have impairments, disabilities or mental health disorders, and we acknowledge that violence does not occur only within the context of poverty. Violence occurs in all societies, it involves the rich and poor, all ages, and is world wide in the history of humanity. Although, the focus of this paper is to understand the risk conditions, which **exist** when there is poverty, the broader issue to be considered is the factors associated with the profound inequalities associated with poverty. One needs to consider the levels of poverty, especially chronic poverty, and how it affects peoples' quality of life and is related to impairments, leading to disabilities or mental health disorders, or to maltreatment. We know that many poor people do not have developmental disabilities, do not respond with violence to stress and frustration because they have good coping skills or resilience strategies to deal with poverty and disability. At the same time we need to focus on structural causes (social exclusion, limited resources, low expectations, social isolation, lack of support) that interact with the personal and immediate causes (level of health, education, skills, abilities, self-esteem) that produce multiple privations. Different dimensions of poverty, related to education, health, shelter, environmental infra-structure, employment conditions, income, emotional well-being, among others, interact with each other producing different privations of that negatively affect people in an intergenerational way. The lack of material resources and poor social conditions is associated with negative attitudes, values, ways of behaving and reflect a culture of poverty.

Intense social vulnerability is frequently associated with low expectations, poor self-esteem, resignation, resentment of the more financially and socially advantaged. Social exclusion is central to understanding a culture of poverty. Buchardt, Le Grand, Piachaud, according to Costa & Carneiro¹⁴, analyzed the evolution of the social exclusion concept and defined it in three ways: (1) to designate those who are outside of the margins of the social protection system, without access to protective nets (concept from France); (2) the presence of an underclass, the social marginalization of people with personal, values and behavioral characteristics related to the social production of the marginalization culture (concept from USA); (3) groups who are lacking basic rights and have difficulty accessing these rights (concept from international organizations). The three concepts are interesting as they identify and articulate the various aspects of this

multidimensional problem. Poverty and social exclusion challenge public policies to deal with a multiplicity of inequalities, not thinking only in terms of class divisions, with one-dimensional and linear polarization, but as phenomena that should be seen much more as a process related to interactive factors and shifting conditions¹⁴. From a public policy perspective it is necessary to invest in education, health, poverty and inequality reduction programs, in order to change the culture of poverty. This is the broad-based approach necessary to addressing those factors inherent in this culture that lead to human privation, to diminishing the individual and his/her capabilities leading to the generational perpetuation of a culture of poverty.

The use of the term new morbidity has been introduced into the literature to describe the association between childhood disability and family structure (single-parents are at major risk); poverty; and ethnic, linguistic and cultural status²⁰. "The term also suggests a multipronged approach to addressing the challenges of family quality of life that are related to poverty". Individuals with disabilities are profoundly affected when their quality of life is compromised, especially when there is lack of healthy living conditions and socio-cultural deprivation. Exclusion is one of the greatest challenges faced by persons with disabilities and their families because it contributes to iniquity and isolation. Living a dual realm of disability and poverty exacerbates the multiple privations that lead to more severe impairments and inequalities, perpetuating the cycle of disability and poverty. There is also a strong link between mental health and poverty^{12,13}. As a consequence, one observes the violation of the rights of persons with disabilities, a greater frequency of mental health disorders among the disabled and their families, with the presence and persistence of social marginalization, rejection and exclusion. One would hope that by supporting the disabled and their families, one could help to improve their quality of life thereby reducing the impact of disability and mental health disorders.

Over the past ten to fifteen years the disability movement has grown in terms of the struggle to promote human rights¹³. In LAC it came alongside the democratization process in many countries. Nevertheless, the limitations of the mechanisms that are available for implementing those rights are frustrating. Poverty as well as maltreatment are indicators of the failure of achieving those human rights. One could argue that the eradication, or even reduction, of poverty and violence through the establishment of prevention programs will help to make these rights a reality.

In recent years greater attention has been devoted to the maltreatment of women and children. Unfortunately, little is known about violence against children and youth with disabilities. One study described by the American Academy of Pediatrics ***showed that children with disabilities are 1.8 times more likely to be neglect, 1.6 times more likely to be physically abused, and 2.2 times more likely to be sexually abused than children without disabilities***³³. A recent European study³⁴ noted maltreatment among children with disabilities “as a taboo within a taboo, probably because the association between disability and violence is emotionally difficult to cope with”. On the other hand, according to the authors, violence in families of children with disabilities is difficult to trace and to prevent. Most studies³³⁻³⁷ agreed with the fact that there is inadequate and inaccurate epidemiological data available to give a clear idea of the prevalence of domestic violence against children with disabilities or special health care needs. Although the data are poor, many organizations of and for disabled persons have examples of maltreatment in their day-to-day routine, but only few of them develop a systematic approach to prevention and intervention. So, the issue of violence against children and youth with disabilities should be included on the agendas of organizations in the disability and mental health fields.

Some authors^{34,35,37} believe that it is not the disability per se, that is a risk factor for maltreatment, but that it tends to be of more significance when associated with at least another risk factor, for example the level of social support. They argue that it is the interaction of several risk factors associated with the disabled individual, the family, the environment, the social and cultural circumstances and the family's economic level lead to maltreatment of the disabled child. Several researchers noted the relation between poverty and maltreatment³⁴, even knowing that most people living in poverty do not harm their children. Melton³⁸, in reviewing more than twelve studies of child maltreatment from the last two decades, showed that families in which maltreatment occurs have a multiplicity of serious personal, social and economic problems. In addition, many communities in which maltreated children live are themselves often dangerous and seriously disadvantaged. It should be noted that psychological variables associated with maltreatment, such as depression, low self-esteem, sense of inadequacy, impulsivity, and substance abuse, and/or demographic factors, such as family size, economic resources, among others, are directly related to the ability of families to cope with poverty. The link

between maltreatment and poverty exists but one should consider and not forget that this link is not universal. As noted above, there are many factors, independent of poverty, that are associated with and contribute to maltreatment. Since we are focusing on disability it is important to recognize that there is a link between disability, poverty and maltreatment and that this link reflects the complexity and multidimensionality of the problem thus necessitating an eclectic, cross-disciplinary and broad-based approach to addressing the issues involving government, education, medicine, mental health, social services, employment, among others.

An agenda proposal for disability and mental health field

The design of inclusive policies is at the heart of the new disability strategy in addition to the traditional rehabilitation services, anti-discrimination measures and the provision of social safety nets. New emphasis is being given to the removal of social and environmental barriers that are preventing disabled persons from seizing opportunities for education and advancement. These policies are seen as most cost-effective because they have the potential to increase the income of disabled persons. Although the agenda is already addressing important issues, it is necessary to add other issues, according to the arguments developed in this paper.

Two issues, which are not new, but are starting to be addressed at an international level, should be included in the agenda of disability and mental health field in Latin American and Caribbean governmental and nongovernmental organizations of persons with disabilities. The systematic link between “poverty and disability” needs to be seen as a morbidity that can no longer be ignored. Also, the issue of “disability and maltreatment” should be included on the agenda. It has to be a priority of the public agenda to include the issue of poverty reduction strategies associated with disability and violence prevention programs. Also it is necessary to counteract the lack of information on this multidimensional subject and search to produce statistically valid studies to provide better visibility to this problem in LAC. The disabled population must be explicitly mentioned as “vulnerable” or “marginalized” among the other marginalized groups and must be referenced in the government plans under the strategies and programs to reduce poverty^{12,13,17-19}.

When addressing specifically poverty reduction strategies among people with disabilities and mental health disorders the following have been sug-

gested in recent years¹²: (1) local and community level – organizations for persons with disabilities must take the struggle against poverty maintaining the focus on human rights; gather systematic prevalence information in order to provide a better picture of the magnitude of this problem; strengthen the organizations' capacity to sustain poverty reduction efforts at different levels by lobbying local governmental agencies to financially invest in these efforts; (2) regional strategies – strengthen the information networks and generate knowledge related to the issues of poverty and disability; promote inter-institutional partnerships with the collaboration of government, non-government and international agencies; build in indicators to monitor the efficacy of reduction poverty programs; (3) continental strategies – create alliances between research institutes and universities to highlight and promote research on the poverty-disability cycle.

With respect to interventions to improve the quality of life for persons with disabilities it is recommended¹³: a) improve the health and mobility of disabled persons – ensure infrastructure and facilities; better access to functional rehabilitation centers; develop a community-based rehabilitation program at a national level; b) promote education and training – access to special facilities within schools and universities; schooling for social inclusion, distribution of school supplies, provide scholarship for disabled persons; c) improve economic and social status – provide training and access to employment opportunities; d) combat negative stereotypes – raise awareness of positive life experiences of disabled persons; support organizations that promote the rights of persons with disabilities; develop and implement protective laws.

In order to develop violence prevention programs in the disability and mental health field it is necessary to define the problem, the aims to be achieved, the activities to be undertaken and the expected results. It is important to gather accurate data using uniform definitions and an accepted view and definition of maltreatment. A prevention program should monitor the process and the effects of its activities, which are not easy to predict. Organizations should start by planning internal

discussions, choosing a clearly defined strategy and giving a guarantee of professional support, if necessary. Prevention involves different phases: an appreciation of risk, early detection of signs suggesting that there are stresses and dysfunction that could lead to violence, early intervention and follow up. Follow-up should adhere to specific principles: appropriate timing, flexibility according to the child and family needs, objectivity in assessing risk and protective signs and consideration of the context, the main players and their relationships. Prevention strategies should focus on reducing risk factors and strengthening protective factors and should be done utilizing a multi-disciplinary, integrated and coordinated approach, based on open, honest and rigorous communication between professionals from different disciplines (health, justice, social work, education and special education, among others). The prevention/intervention process must be formalized within the organization³⁵.

Finally^{33,35-37}, each prevention program and its supporting organizations should agree upon a common language, thus reducing the potential for ambiguity concerning the nature and structure of the program, the interpretation of the effects of the program and the meaning and significance of the work. They should consider the following priorities: a) the needs of families should be met at different levels in order to enable them fulfill their fundamental role in the supporting the child's development; b) listening to and understanding the family situation should be followed by concrete support; c) to empower children, recognize their rights, explore their potentialities, enhance their skills; d) to reinforce children's communication, interaction and participation in family and non-family contexts; e) to encourage the development of a network made up of different public institutions, private nonprofit organizations and community/interpersonal resources in the families' and children's interest, with clear roles and responsibilities; f) to alert the general public to the impact and the context of the problem involving children with and without disabilities; g) to help organizations to use their political power to defend the rights of children with and without disabilities.

Collaboration

The proposal and design of this article addressing the issue of poverty and disability were worked by F Cavalcante. The final revision and the issue of disability and maltreatment were developed by E Goldson. The article's discussion and conclusion were done by both authors.

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References

1. Kempe CH, Silverman F, Steele B, Droegemueller W, Silver H. The battered child syndrome. *Journal of the American Medical Association* 1962; 181:4-11.
2. Goldson E, Louch G, Washington K, Scheu H. Guidelines for the Care of the Child with Special Health Care Needs. *Advances in Pediatrics* 2006; 53:165-182.
3. Cavalcante FG, Marinho ASN, Bastos OM, Maimone MS, Deus VV, Valdene RSR, Carvalho MM, Fiaux MP, Reis LHNL, Abrantes IS, Silva MF, Machado ST, Freitas FF, Ávila AT. *Violência e Direitos no campo da Deficiência: Percorrendo os Caminhos de uma Pesquisa*. Relatório Técnico, Volume I. Rio de Janeiro: Claves/Ensp/Fiocruz; 2007.
4. Cavalcante FG, Marinho ASN, Bastos OM, Deus VV, Maimone MS, Carvalho MM, Fiaux MP, Valdene RSR. Diagnóstico situacional da violência contra crianças e adolescentes com deficiência em três instituições do Rio de Janeiro. *Cien Saude Colet* 2009; 14(1):45-56.
5. Bouillon CP, Buvinic M. *Inequality, Exclusion and Poverty in Latin America and the Caribbean: Implications for Development*. IDB Document from EC/IDB Seminar: Social Cohesion in Latin America and the Caribbean; 2003.
6. Engel W. *Estratégias de Redução da Pobreza e da Desigualdade na América Latina e no Caribe*. In: V Assembleia Plenária do Forum Interparlamentar das Américas/FIPA. Bogotá, Colômbia: Banco Interamericano de Desenvolvimento; 2006.
7. Londoño JL, Székely M. *Persistent Poverty and Excess Inequality: Latin America, 1970-1995*. Working paper 357. Washington, D.C.: Inter-American Development Bank; 1997.
8. Janvry A de; Sasoulet E. *Growth, Poverty, and Inequality in Latin America: A causal Analysis*. 1970-94. In: Conference on Social Protection and Poverty. Washington, D.C.: Inter-American Development Bank; 1999.
9. Klisberg B. *América Latina: uma região de risco - pobreza, desigualdade e institucionalidade social*. Brasília: UNESCO; 2002.
10. Attanasio O, Székely M. *Portrait of Poor: An Assets-Based Approach*. Washington, D.C.: Inter-American Development Bank; 2001.
11. Barros RP, Henriques R, Mendonça R. *A estabilidade inaceitável: desigualdade e pobreza no Brasil*. Texto de Discussão No 800. Brasília: Ministério do Planejamento, Orçamento e Gestão/ IPEA; 2001.
12. Richler D. *The Status Report on Poverty and Disability in the Americas: Voices from the Americas*. United Kingdom: University of East London/Inclusion International; 2004.
13. Wolfensohn JD. *Poverty reduction strategies: their importance for disability*. Washington, D.C.: Disability and Development Team; 2004.
14. Costa BLD, Carneiro CBL. *Implicações do enfoque da exclusão social sobre as políticas públicas: desafios para o desempenho governamental*. Texto para discussão nº 08. Belo Horizonte: Escola de Governo da Fundação João Pinheiro; 2004.
15. Monteiro CA. A dimensão da pobreza, da desnutrição e da fome no Brasil. *Estudos Avançados* 1995; 9(24):195-207.
16. WHO. A29/INF/DOC3. Geneva: WHO; 1976.

17. Metts R. *Disability Issues. Trends and Recommendations for the World Bank*. Washington, D.C.: World Bank; 2000.
18. Elwan E. *Poverty and disability – a survey of the literature*. Washington, D.C.: World Bank; 1999.
19. Yeo R. *Chronic Poverty and Disability*. Action on Disability and Development (ADD). Manchester: Chronic Poverty Research Centre; 2001.
20. Park J, Turnbull AP, Turnbull III HR. Impacts of Poverty on Quality of Life in Families of Children with Disabilities. *Council for Exceptional Children* 2002; 68(2):151-170.
21. Schalock RL. Can the concept of quality of life make a difference? In: Sahclock RL, editor. *Quality of Life. Volume II: application to persons with disabilities*. Washington, D.C.: American Association on Mental Retardation; 1997. p. 245-267.
22. Schalock RL. Three decades of quality of life: Mental retardation in the 21st century. In: Wehmeyer ML, Patton JR, editors. *Mental retardation in the year 2000*. Austin, Texas Pro-Ed; 2000. p. 335-356.
23. Bailey DB, McWilliam RA, Darkes LA, Hebbeler K, Simeonsson RJ, Spiker D, Wagner M. Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children* 1998; 64:313-328.
24. Federal Child Abuse Prevention Act 42. United States Code 5106g (4); 1974.
25. Helfer R. The epidemiology of child abuse and neglect. *Pediatric Annals* 1984; 13:745-751.
26. National Center of Child Abuse and Neglect. National report of suspected abuse against children. Englewood: National Center of Child Abuse and Neglect; 2004.
27. Commentary. A New Definition of Children with Special Health Care Needs *Pediatrics* 1998; 102:137-140.
28. Buvinic M, Morrison AR, Shifter M. Violence in the Americas: a framework for action. In: Morrison A, Biehl M, editors. *Too close to home*. Washington, D.C.: Interamerican Development Bank; 1999.
29. Abramovay M, Castro MG, Pinheiro LC, Lima FS, Martinelli CC. *Juventude, violência e vulnerabilidade social na América Latina: desafios para políticas públicas*. Brasília: UNESCO/BID; 2002.
30. Westcott H. The abuse of disabled children: A review of the literature. *Child Health Care Deve*.1991; 17:243-258.
31. Resnick MD. The Social Construction of Disability. In: Blum RW, editor. *Chronic Illness in Childhood and Adolescence*. Orlando, Florida: Grune and Stratton; 1984. p. 29-46.
32. Sobsey D. *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance*. Baltimore: Paul H. Brookes Publishing Comp; 1994.
33. American Academy of Pediatrics. Assessment of Maltreatment of Children with Disabilities. *Pediatrics* 2001; 108(2):508-512.
34. AIAS Bologna Onlus, Fenacerci, Disability Now & Disminuidos Físicos de Aragón. *Childhood, Disability & Violence Project. Empowering disability organizations to develop prevention strategies. Full Report*. European Commission: Daphne Programme; 2004.
35. Goldson E. Maltreatment among children with disabilities. *Infants and Young children* 2001; 13:44-54.
36. UNICEF. Violence against Disabled Children. UN Secretary Generals Report on Violence against Children Thematic Group on Violence against Disabled Children. Findings and Recommendations. Summary Report. New York: United Nations; 2005.
37. Gonzalvo GO. Qué se puede hacer para prevenir la violencia y el maltrato de los niños con discapacidades? *An Pediatr* (Barc) 2005; 62(2):153-157.
38. Melton GB. Mandated reporting: a policy without reason. *Child Abuse & Neglect* 2005; 29:9-18.