A systematic review of generic and special needs of children with disabilities living in poverty settings in low and middle- income countries

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Abstract

Children with disabilities living in poverty settings in low and middle-income countries are

particularly in need of special support designed to meet the needs occurring in an environment

where poverty is prevalent and resources are scarce. This article presents a systematically

review the needs of children with disabilities living in poverty settings in low and middle-

income countries using Maslow's Hierarchy of Needs as a theoretical framework. The

findings demonstrate that needs at the first level of Maslow's Hierarchy of Needs are more

frequently researched in low and middle-income countries. Higher order needs should be

further explored and children's own voices should be taken into consideration when

performing research, designing policies and services aiming at increased service user

empowerment.

**Keywords:** Child disability, intellectual disability, needs, low and middle- income countries

## Introduction

Poverty is both a cause and a consequence of disability (Emmet, 2005) due, in part, to the mutual reinforcement of these two conditions. The heightened exposure to risks and environmental hazards related to poverty can increase the likelihood for congenital or acquired disabilities, while disability can reinforce poverty through its negative association with education and employment. The World Bank classifies its member countries as low-, middle or high-income countries. The classification is based on Gross National Income (Chandran, Herbert, Lee, Rudan, & Baqui, 2011). According to the World Bank, low- and middle-income countries (LAMI-countries) are also sometimes referred to as developing countries (The World Bank, 2012). The term LAMI-countries will be used in this manuscript. The mutual relationship between poverty and disability is particularly evident in LAMI countries where poverty is prevalent and resources are scarce when compared to the needs of the people. Poverty has been suggested to be ubiquitous in these countries; in fact, where up to 50% of their population's exhibit stunted growth from a lack of proper nutrition (Walker et al., 2007).

Estimates suggest that 126 million children in LAMI countries live in absolute poverty (i.e., less than US\$1 per day) (Grantham-McGregor et al., 2007). To illustrate how poverty can stymie the fulfilment of children's needs, some researchers (e.g., Prince & Howard) (Prince & Howard, 2002) have used Maslow's Hierarchy of Needs (Maslow, 1943) as a

framework. This hierarchy is comprised of five levels, starting with physiological needs, followed by safety needs, love and belonging needs, self-esteem needs, and self-actualisation needs (i.e., fulfilling one's potential) at the top of the hierarchy. Research in to poverty has used this hierarchy with the rational that is a useful basis for to understand what needs to investigate, i.e. in poverty settings more basic needs are in focus because these dominate peoples thoughts. However, Maslow (Maslow, 1943), in his original work, goes on to explain that these are cross-cultural basic needs and that while most people must fulfil lower level needs before advancing to another level (e.g., the fulfilment of physiological needs before safety needs), this is not true of every individual. Thus, earlier research may have been biased towards primarily investigating basic needs and consequently there is a knowledge gap concerning the relations between more advanced needs (e.g. self-actualisation needs) and poverty.

In order to highlight how poverty creates barriers in the fulfilment of American children's basic needs, Prince and Howard (Prince & Howard, 2002) used Maslow's theory as a framework. When discussing physiological needs, for example, they suggested that while it would be very uncommon for a child to die of starvation in the United States, poor children often do not eat an optimally nutritious diet, which promotes healthy development. Poverty also presents obstacles to the fulfilment of children's safety needs by both physical (e.g., environmental toxins) and social (e.g., violence, negative peer influences) means.

Furthermore, the stress that comes with living in such areas may drain the emotional resources of children's primary caregivers and leave them unable to satisfy the love and

belonging needs of their children. Growing up in poverty also is a leading risk factor for school difficulties which can damage children's self-esteem, and prevent them from realizing their potential (i.e., self-actualisation needs).

The widespread poverty found in the developing world exponentially increases the likelihood of childhood morbidity or mortality in these countries. It has been estimated, for instance, that up to 200 million children younger than five years of age living in Asia and Africa fail to reach their cognitive potential as a result of economic disadvantage, malnutrition and poor health (Grantham-McGregor et al., 2007). Children with disabilities in these regions may be even more vulnerable since they frequently have additional, special needs over and above their basic needs and less than 5% of children with disabilities in LAMI countries have access to rehabilitation services (Maloni et al., 2010). According to The International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY) disability covers a spectrum of various levels of functioning at body level, person level and societal level (WHO, 2007).

Although the definition of special needs varies depending on the source, a broad definition of special needs was chosen which defines children with special needs as having one of the following: 1) children with identified disability, health or mental health conditions requiring early intervention, special education services or other specialized services and supports; or 2) children without identified conditions but requiring specialized services, support or monitoring (California State definition of special need, 2012).

The voice of children has traditionally not been included in child-related research. Because it is important to incorporate input from the individuals who are the focus of research themselves, our understanding of child health is incomplete (Irwin & Johnson, 2005; Woodgate, 2001). Previous research concerning children's quality of life has revealed that parents both under- and overestimate children's quality of life when compared to the scores that children provide (Petsios et al., 2011; Sattoe, van Staa, Moll, Own Feet Res, & On Your Own Feet Research, 2012; Weissberg-Benchell et al., 2009) Because parent and child scores are not equivalent, it may be important to ask children for their opinions on research about themselves. It has been found that typically developing children as young as three years of age can provide graphic descriptions about experiences they have had (Docherty & Sandelowski, 1999).

## Aim

The aim of this study was to systematically review the needs of children with disabilities living in poverty settings in LAMI countries that have been identified by empirical research published within the last ten years (2001-2011).

# Method

Study design

This paper presents a systematic review of the literature using database keyword searches. The selection of studies was then refined using an inclusion and exclusion protocol on both abstract level and full-text level.

## Literature search

Keyword searches were performed in the following databases: Eric, Psych Info, and Cinahl. These databases were selected after consulting librarians with the aim of our study as to have the best academic resources available. The search was done in Sweden in February 2012 and the following key word search terms were used in all three databases: child \*, disab\*, need\*, poor or poverty, LAMI countr\*, or developing countr\* (see Table 1 for the search results). The limitations chosen to get the research available within the last ten years were that the article should be peer reviewed, written in English language and have a publication date between January 2002 and December 2011. The relevance of chosen search terms was explored based on the aim of the study (i.e., the identification of the needs of children with disabilities in LAMI -countries). The theoretical and practical relevance of the search terms were confirmed after discussions between the authors, experts in the field, and librarians.

Table 1. Search results

Data- base	Potentially included	Included at abstract level	Included at full text	
Eric	117	7	2	
Psychinfo	240	11	1	
Cinahl	230	14	8	
Total	587	32	11	

Inclusion and exclusion criteria

The search results were exported and sorted using inclusion and exclusion criteria on abstract and full text level.

An exclusion/inclusion protocol and mapping protocol for abstract and full-text level was developed, in part, using the Mac Master critical review form for qualitative and quantitative studies (Mac Master University, 2012). The perspectives of the children, the primary caregivers (Woodhouse, 1994) and the service providers (e.g. therapists, teachers, rehabilitation personnel) were added to the protocol. Also the needs hierarchy as described by Maslow in Prince and Howard (2002) were included in the protocol. The protocols aimed to ensure a standardized qualitative and quantitative content analysis of the articles. The authors chose to include articles that described both specific impairments and disabilities without further specification. Three of the authors read the first 100 abstracts to establish sufficient

interrater reliability to ensure the consistency of the articles included. Two out of three authors then implemented quality assessments on a full-text level using the data extraction protocol.

Protocol at abstract level: The inclusion criterion included articles describing children between birth and 18 years of age with disabilities. The exclusion criteria on abstract level were threefold: 1) the article was not an empirical study, 2) the study was not about a LAMI country, according to the World Bank's definition (The World Bank, 2012) or 3) the article addressed a specific medical treatment or a specific educational technique such as a teaching method or intervention. Review articles were also excluded. The authors chose to include both qualitative and quantitative studies in order to increase the number of possible articles to include.

#### *Protocol at full text level:*

The protocol on full text level included two parts; 1) relevance and quality and 2) mapping (the content of the articles). The *relevance* (by this we mean the appropriateness in relation to our aim) was graded on a three-point scale (high, middle and low). The grading was based on the following criteria: 3) high, fully answering the aim of our review, 2) middle, partially answering the aim of our review and 1) low, not answering the aim of our review. Articles considered to be of low relevance to the systematic review were excluded. The *quality* was also assessed from a three-point scale, low, middle and high. The following methodological aspects were taken into consideration: 1) the study design, 2) the population and sampling and

3) the validity and reliability. If all three of these aspects were described the quality grading was considered high, if two of the aspects were well described the quality grading was considered as of middle -quality and if only one of the above aspects were described the grading was considered as of low-quality. Articles also considered to be of middle quality were included due to the low number of articles found in the search. Articles considered as of low quality were excluded. See table 2 for an overview of included studies. *The mapping part of the protocol* included a description of which level of Maslow's hierarchy that were threatened as a consequence of poverty, how poverty and disability were defined and whose perspective that was used (children's, primary caregivers or service providers, e.g. therapists, teachers or rehabilitation personnel) as well as a summary of the most important results and conclusions.

## Data analysis

The analysis was a deductive content analysis based on Maslow's Hierarchy of Needs (Maslow, 1943) for children with disabilities in LAMI-countries (The World Bank, 2012).

The analysis also included who reported on the children with disabilities' needs, namely the children themselves or a primary caregiver and/or a service provider. The identified needs were divided into generic needs (i.e., needs of all children irrespective of whether they have a disability or not) or a special need (i.e., additional needs of children with disabilities). In this process, potential barriers and facilitators of children having their needs met were also identified and included in the analysis. The eleven articles included studies

Table 2. Overview of included studies, organized in alphabetical order.

<sup>\*</sup>Quality includes a grading of the included article's description of the study design, population and sample and if validity and reliability aspects are addressed. Please see the method section for further description of the relevance and quality grading.

Author, Year	Aim	Study design	Population and Sample	Relevance*	Quality *
Deng M., Holdsworth JC., (2007)	To map the rout undertaken by the Project Management Office of the Gansu Basic Education Project (GBEP) in order to ensure that managers, schools and teachers can provide good learning opportunities for children with special educational needs.	Mixed (both qualitative and quantitative) but the results are mainly from the qualitative part	50 head teachers and teachers in the Gansu- province, China Ages of children not applicable	High	Middle
Hartley S., Ojwang P., Baguwemu., Ddamulira M., Chavuta A., (2005)	To provide an evidence-based footing for the future development of CBR practice.	Qualitative (phenomeno- logical design)	52 families of children with disabilities in one urban and two rural districts in Uganda  Age of children not stated	High	High

<sup>\*</sup>Relevance refers to the included articles aim's relevance in relation to the aim of this review

Kristensen K., Omagor-	To evaluate the capacity of the	Qualitative	Head teachers,	Middle	High
Loican, M., Onen, N., (2006)	existing special schools in		teachers, support		
	regard to basic requirements		staff and learners		
	and minimum standards		in 11		
	indicators; to develop proposals		Government- aided and four		
	for the existing and new special schools to meet basic		private primary		
	requirements and minimum		special schools in		
	standards; and to examine the		Uganda Uganda		
	future use of special schools as		Gundu		
	resource centers in support of an inclusive education system.		21 learners		
	an metasive education system.		Ages 6-12		
Kromberg J., Zwane E.,	To investigate the prevalence	Quantitative	6692 children in	Middle	High
Manga P., Venter A., Rosen	and types of childhood		3405 households		C
E., Christianson A., (2008)	disability in a rural population		in the Bushbuck-		
	as well as the knowledge,		ridge district,		
	beliefs and practices of local		South Africa		
	traditional healers regarding		A C 1 11		
	these disabilities. Further, to make recommendations for		Age of children: 2-9 yrs.		
	health services and policy		2-9 yis.		
	makers.				
	makers.				

Maloni P.K., Despres E.R., Habbous J., Primmer, A.R., Slatten J.B., Gibson B.E., Landry M.D., (2010)	To describe perceptions of disability among mothers of CWD in Bangladesh, and to explore how these perceptions influence the care sought for their CWD.	Descriptive qualitative	Eleven mothers of children with disabilities Age of children 2-10 yrs. Bangladesh	High	High
Norgrove P., Zulianello R., Dreise,M., Steenbeek M., (2007)	To report on the development of a program to treat and rehabilitate children with chronic orthopaedic disabilities in the sub-Saharan African context incorporating orthopaedic reconstructive surgery within community-based rehabilitation programs.	Quantitative	5004 children, Uganda  Age of children not stated	Middle	High
Saetermoe CL., Gomez J., Bamaca M., Gallardo C., (2004)	To explore the experiences of lower middle class Ladino and Indigena parents and care givers of adolescents with severe physical disabilities negotiating Guatemala's urban health care and educational systems.	Qualitative	15 families in Guatemala City Ages of adolescents 12- 21 yrs.	Middle	High
Salojee G.,Phohole M., Salojee,H., Ijsselmuiden C., (2006)	To assess the unmet rehabilitation, education and welfare needs of disabled children living in a peri-urban township.	Mixed methods (both qualitative and quantitative)	156 children in Orange Farm Township, South Africa Age of children 0-18 yrs.	High	High

Shoaib M., Yazdanie N., Khan AA., Kaleem OH., Ibrahim N., Azad B., (2006)	To investigate the oral health status of individuals with intellectual and medical disabilities in Lahore and compare these results with an age and gender matched healthy control group	Quantitative, cross sectional study	424 children with intellectual impairments and Down syndrome  Age of children 6-17 yrs.	Middle	High
Van Rie A; Mupuala A; Dow A, 2008	To compare the neurodevelopment of preschool-aged HIV-infected, HIV-affected (HIV-uninfected AIDS orphans and HIV-uninfected children whose mother had symptomatic AIDS), and healthy control children in Kinshasa, Democratic Republic of Congo	Quantitative	160 children with and without HIV-infection, Age of children 18-72 months.	Middle	Middle
Yousafzai AK., Pagedar S., Wirz S., Filteau S., (2003)	To develop an understanding of the local culture and to plan an intervention suited to the environment that would improve the nutritional wellbeing of children with disabilities in the future.	Qualitative	10 community health workers, 13 carers of children with disabilities, 18 carers of children without disabilities in the slum population of Dharavi, India Age of children not stated.	High	High

from Uganda (n = 3) South Africa (n = 2), Guatemala, Pakistan, India, Bangladesh, China and the Democratic Republic of Congo (n = 1 each). The articles were all published between 2003 and 2010.

#### **Findings**

The included articles relevance and quality grading were: high relevance (n = 5) middle relevance (n = 6), high quality (n = 9) and middle quality (n = 2). The results are presented in the structure of Maslow's hierarchy; with physiological needs first, followed by safety needs, love and belonging needs, self-esteem needs and self-actualisation needs. As each need is introduced, it will be discussed as a generic need or a special need. The needs are mainly structured as those mentioned by the primary caregivers, then the service providers ending with the needs from the children themselves (one article). However, the results are in some cases described from articles that were written from two perspectives and these perspectives are then presented in the same paragraph.

## Level 1: physiological needs

Physiological needs were addressed in ten of the eleven articles (see Table 3). The first results presented are from the primary caregivers' and service providers' perspectives.

The struggle to fulfil the first level of generic needs was described by primary caregivers and service providers in terms of how poverty restricted their children's access to food, clothes,

**Table 3. Identified needs and perspectives.**\* Generic needs; needs of all children. \* Special needs; additional needs required by children with disabilities.

Author	Level 1: Physiological needs	Level 2: Safety needs	Level 3: Love and Belonging needs	Level 4: Self- esteem needs	Level 5:Self- actuali- zation needs	Generic (G)/ Special (S) Need *	Perspective; (Primary Caregivers, Service Providers, Children's)
Deng & Holdsworth, 2007		X		X		S	Service providers
Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005	X Generic need	X	X	X		G,S	Service providers Primary Caregivers
Kristensen, Omagor-Loican, Onen, & Okot, 2006	X		X	X		S	Service providers Children's
Kromberg, Zwane, Manga, Venter, Rosen, Christianson, 2008	X					S	Service providers
Maloni, Despres, Habbous, Primmer, Slatten, Gibson, Landry, 2010	X					S	Primary Caregivers
Norgorve, Zulianello, Dreise, & Steenbeek, 2007	X					S	Service providers
Saetermoe, Gómez, Bámaca, & Gallardo, 2004	X			X	X	S	Service providers Primary Caregivers
Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007	X				X	S	Primary Caregivers
Shoaib M; Yazdanie N; Khan AA; Kaleem OH; Ibrahim N; Azad B, 2006	X					S	Primary Caregivers
Van Rie, Mupuala, & Dow, 2008	X		X			S	Primary Caregivers
Yousafzai, Pagedar, Wirz, & Filteau, 2003	X Generic need	X	X		X	G,S	Primary Caregivers

and bodily care. The primary care givers of children with severe disabilities helped the children with activities such as eating, washing and toileting (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). The generic needs of children with disabilities also were threatened by poverty through a lack of nutrition and inadequate food. Having access to clean water and electricity were described as generic needs for all children, and primary caregivers reported that the needs of children with disabilities were often not considered in the local area (Yousafzai, Pagedar, Wirz, & Filteau, 2003). In addition, one article highlighted the service providers' perspectives on the basic physiological needs of children with disabilities living in poverty. The article noted how children with HIV/AIDS who lived in high levels of poverty exhibited malnutrition and stunting (Van Rie, Mupuala, & Dow, 2008).

The next section highlights the primary caregivers' and service providers' perspectives on special needs. As feeding can sometimes be difficult for children with disabilities, the importance of having a primary caregiver with accurate knowledge about how to feed the child was highlighted in one article where primary caregivers were interviewed (Yousafzai et al., 2003). Service providers as well as primary caregivers reported on the special needs of children with disabilities and stated that these were often described in terms of lack of access to assistive devices such as wheelchairs, hearing aids, communication aids, specialized seating and standing frames (Hartley et al., 2005; Saetermoe, Gómez, Bámaca, & Gallardo, 2004) which can potentially impact negatively on children's physiological needs in terms of restricted mobility and limitations of self-care (Hartley et al., 2005). Poverty affected the families' possibilities of accessing rehabilitation and health care for their children with

disabilities as transport to health care sites was often seen as too expensive; this was also described from both the primary caregiver's perspective as well as the service provider's perspective (Hartley et al., 2005; Kromberg et al., 2008; Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007; Yousafzai et al., 2003). The need of improved oral hygiene was described in one article (Shoaib et al., 2006) where the primary care givers revealed that children with intellectual impairment had significantly poorer oral hygiene when compared to typically developing children. Primary caregivers also mentioned the need for information about disability, as the lack of understanding about the causes of disability and the permanence of disability created delays in seeking healthcare services for children with disabilities (Yousafzai et al., 2003). Misinformation about disability was highlighted in one study taken from the primary care giver's perspective, where mothers in the sample held the belief that their child's disability was temporary and looked for ways to "cure" the disability and make the child "normal" (Maloni et al., 2010). Proper diagnoses and subsequent medical treatment at an early age was emphasized in several articles from both the primary caregivers and the service provider's perspectives (Hartley et al., 2005; Kromberg et al., 2008; Penny, Zulianello, Dreise, & Steenbeek, 2007). In some cases, as reported from both the service providers' and primary caregivers' perspective, receiving a correct diagnosis took a significant amount of time, which exacerbated the condition (Saetermoe et al., 2004).

Special needs were described by the service providers and the children themselves as the need of assistive devices such as hearing aids, Braille, hand-frames and wheelchairs.

Some of the schools where children needed assistive devices expected the parents to provide

these devices for their children. The children themselves also stated that it could be an advantage for children who are deaf to be taught in a special school because they received better instruction when compared to general education schools. The children also said that as a result of the teachers' special education training, the school environment was friendly with good relationships and a good collaboration between the children and teachers. Further, the children reported that teachers rendered a large amount of support and assistance to them during learning or when they were sick (Kristensen, Omagor-Loican, Onen, & Okot, 2006).

# Level 2: safety needs

Generic needs related to safety issues were addressed by the primary caregivers and service providers in three articles (Deng & Holdsworth, 2007; Hartley et al., 2005; Yousafzai et al., 2003). The immediate future was of great concern for primary caregivers struggling to earn money for daily needs and seeking treatments for their child. From the primary caregivers' perspective, the anxiety of not knowing who would take care of the child while the mother was at work and in the long-term future, when she passed away was addressed in one study (Yousafzai et al., 2003). For children living in a community where members held beliefs those children with disabilities were shameful, embarrassing and that they should be hidden, the children were at risk of isolation and loneliness. Peers also abused some of the children in these cases. The need of freedom from fear and anxiety of being bullied because of the disability was highlighted from the primary caregivers' perspective (Hartley et al., 2005). This was also addressed in another article (Deng & Holdsworth, 2007) but from the

service providers' perspective, where teachers and local head teachers were interviewed. The children's perspectives on safety needs were not addressed in these included articles.

## Level 3: love and belonging needs

Love and belonging needs were addressed in four of the eleven articles (see Table 2) and were discussed by the primary caregivers and children in terms of the generic need for socialization, for example, spending time with friends and playing sports (Hartley et al., 2005; Kristensen et al., 2006). Primary caregivers described special needs as the importance of being accepted in the neighbourhood and in school despite the child's disability. For children with communication impairments, the primary caregivers expressed concern about the limited means through which the child could express him/herself (Hartley et al., 2005). Acceptance was sometimes dependent upon the severity and nature of the disability; for example, children with speech impairments were described as particularly vulnerable since they were not always accepted or understood by the people in the environment (e.g., a child displaying challenging behaviour like hitting as a means of communication) (Yousafzai et al., 2003). One study revealed primary caregivers' feelings of shame about having a child with disability and attributed the cause of disability to past sin.

When reporting on their special needs, children in special schools reported that difficulties with special schools included unaffordable fees (due to poverty of parents). The children also said that they felt neglected by their parents when being admitted to boarding special schools (Kristensen et al., 2006).

When the service providers were reporting on children's generic needs, they suggested that positive parent/child interactions were described as being threatened by HIV/AIDS, poverty and poor living conditions, which all contributed to fewer positive parent/child interactions conducive to the child's development (Van Rie et al., 2008). Special needs of love and belonging from the service providers' perspective were not described in the included articles.

#### Level 4: self-esteem needs

Self-esteem needs were also addressed in four of the eleven articles; similar to level 3 needs (see Table 2). Generic needs for children's self-esteem were not mentioned in any of the articles. The special needs of children with disabilities, on the other hand, were described as the need for tolerant and educated social environments (Hartley et al., 2005; Saetermoe et al., 2004). One study addressed the importance of having primary caregivers with sufficient skills and knowledge about the child's disability. The same study described negative attitudes from the fathers and the family concerning the child's disability, and that one explanation for the cause of the disability could be witchcraft (Hartley et al., 2005). Other threats for not fulfilling self-esteem needs were described in one study as stigma and insults about disability as common for children with disabilities (Saetermoe et al., 2004).

Service providers' perspectives for children's special needs were also described in two articles. These studies stressed the importance of people (in society and at school) being knowledgeable about disability and having positive attitudes toward schooling for children

with disabilities in order to fulfil self-esteem needs. The special needs of children with disabilities include school organizations where teacher's salaries were not dependent on the performance results of the class and where the teachers have adequate knowledge on inclusive education (Deng & Holdsworth, 2007; Kristensen et al., 2006). The children's perspectives on self-esteem needs were not addressed in the included articles.

## Level 5: self-actualisation needs

Self-actualisation needs were addressed in three of the eleven articles (see Table 2). Generic needs for children's self-actualisation were not addressed in any of the articles. In regards to primary caregivers' perspectives on children's special needs, one of the included studies described that children with severe disabilities have special needs in being challenged, advocated for, encouraged, educated and positively challenged in order to prepare for adult roles. Primary caregivers and siblings were important role models as were members in the neighbourhood and schoolmates. An orientation toward the future in terms of school and occupation were strongly influenced by the amount of economic resources available in the family (Saetermoe et al., 2004). Financial and practical constraints for school attendance were addressed, because sometimes schools were too far away to make it practical for children to attend them. This same article also addressed concerns of parents of children with disabilities worrying about the immediate future in terms of seeking treatments while the concern for the long-term future was mostly related to who would look after their child when they passed away (Yousafzai et al., 2003). One of the studies showed that children with disabilities were sometimes rejected from school due to the disability (Hartley et al., 2005).

The service provider's perspective and the children's perspectives on self-actualisation needs were not addressed in the included articles.

# Discussion

This systematic review explored both the generic needs and special needs of children with disabilities in poverty settings in LAMI countries. Out of the eleven articles included, six looked at the primary caregiver perspective and seven at the professional perspective (some looked at both) while only one article looked at the child's perspective, and that was the child together with the service providers (Kristensen et al., 2006). Generic needs at the first level of Maslow's hierarchy of Needs were the most frequently occurring needs asked about in the included articles. This finding could be attributed to different factors. Perhaps generic needs were the most frequently occurring because it was easier to study the more tangible generic needs of children with disabilities rather than trying to elicit more abstract concepts such as love and belonging or self-actualisation. On the other hand, higher-order needs such as selfesteem and self-actualisation may not yet be an area of research focus in LAMI countries where generic needs still are hard to fulfil. Maslow stresses that; although generic needs are in lower end of the hierarchy some higher order needs may occur even though lower order needs are not fulfilled (Maslow, 1943). The fact that few studies asked about higher order needs indicate that such studies need to be implemented. The low number of studies focused on higher order needs may also be explained by the fact that more or less only service providers

or parents were respondents. A valid view of higher order needs may require that the children themselves are involved in data collection.

The results point out that descriptions of special needs related to physiological needs are more frequently occurring than descriptions of special needs related to higher-order needs. In terms of physiological needs, generic needs such as feeding sometimes was framed as a special need since primary caregivers reported concern about their child's health in the future and the need of someone with sufficient competence to take care of their child if they no longer were capable of doing so (Yousafzai et al., 2003). This finding stressed the importance of service planning and intervention including information on the disability to relatives or others who could become possible primary caregivers for the child in the future. Special physiological needs were commonly described in terms of the need of assistive devices, such as hearing aids or wheelchairs.

The result shows that many of the needs of children with disabilities in LAMI countries might be threatened by intolerant societal attitudes. Since the results showed that children with disabilities are at risk of being bullied in a society where disability is seen as shameful and embarrassing (Hartley et al., 2005), the need of a tolerant environment is as important as the need for socializing and playing with friends (Hartley et al., 2005; Kristensen et al., 2006). This is also described in a study made by Coleridge, describing that in some cultures disability is seen as a result of a past sin or a curse and girls with disabilities are more vulnerable than boys with disabilities (Coleridge, 1993). In order to fulfil self-esteem special needs, the results suggest the need of an inclusive school environment, where the children's

achievements do not form the basis for the teachers' salaries as this "performance pay" can engender negative attitudes in teachers toward including children with disabilities in their classes.

Self-actualisation needs were related to school attendance. The results show that the special needs of some children with disabilities in LAMI countries (i.e., particularly those who have physical impairments) are in terms of school transportation needs that are not prohibitively expensive. Preparing for adult social and work life also were special needs of children with disabilities. Understanding these needs from the children's perspective could greatly inform and benefit service planning and interventions.

# The children's perspective

Only one of the eleven articles included the children's own perspective where the children were asked about their opinions on attending a special school, e.g. the support being provided and existing attitudes and knowledge on disability (Kristensen et al., 2006). This could be explained in several ways. Firstly, in this study, children were seen as any individual from birth to 17 years of age. Younger children might not be expected to provide their perspectives about their needs. In a similar vein, it may be easier to study children's needs from the perspectives of their primary caregivers or service providers who provide healthcare services, education, and/or interventions for them. However, increasing attention has been given to the importance of researching children's perspectives, as well as the perspectives of primary caregivers and service providers, because it is important to receive input from the actual individuals who are being studied. Still another reason could be that the idea of asking

children about their lived experiences is not yet seen as an important or necessary thing to do. However, discovering the lived experiences of persons is an important aspect necessary for successful intervention and also, when addressing higher order needs it children themselves should be asked about their own opinion in relation to their experience of health and quality of life. Furthermore lived experience of children may differ from what their primary caregivers or service provider's report (Petsios et al., 2011; Weissberg-Benchell et al., 2009).

One could also assume that the possibility of fulfilling the generic and special needs of children with disabilities is affected by the professional's view of disability. However one should bear cognizance of the ethical issues that can potentially occur when exposing children's voices. Asking children about their current life situation may require a plan for follow-up on children and families.

## *Limitations of the study*

There were a couple of limitations to this study. This review included only eleven articles. Many articles were excluded because they were not related to LAMI countries. Using Maslow's Hierarchy of Needs as a theoretical framework in the analysis might also have had a limiting effect on the number of articles included. Specific diagnoses were not included in the search terms; instead general search terms for disability were used.

## Recommendations for further research

The authors suggest that more studies should focus on children with intellectual disabilities. Further studies should focus on the children's own voices about their experiences

and needs as Article 12 of the UNCRC suggests. According to Article 23 each child should enjoy a life promoting the possibilities to actively participate in society (UNICEF, 1989). More studies should therefore not only focus on the first level of Maslow's Hierarchy of Needs but also on safety needs, love and belonging needs, self-esteem needs and self-actualisation needs. Moreover, the interdependency between parents' rights and children's rights is challenging and thus should be further explored according to UNCRC Article 5 regarding respecting the rights and duties of primary caregivers (UNICEF, 1989)

#### Conclusion

This systematic review of the literature has demonstrated that there is room for further studies on the children's own voices including children with intellectual disabilities. Further, the results of this systematic review show that both basic and special needs at the lowest levels of Maslow's Hierarchy of Needs are more frequently researched in LAMI countries, whereas higher-order needs are not. This suggests a demand for more research into children's higher-order needs (i.e., feelings of love and belonging, self-esteem, and self-actualisation). Moreover, efforts have been made worldwide to improve the situation for children with disabilities, yet for the most part, children's own voices have not been heard in this type of research. The voices of children with disabilities should be included when possible in order to expand continuing research aiming at ensuring that their needs are fulfilled. The authors plan to do further research in the area together with colleagues from South Africa who have interviewed children with intellectual disabilities on their own views of their rights. By

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obtaining the multiple perspectives of children, primary caregivers, and service providers, the needs of children with disabilities in LAMI countries may be better addressed.

# Acknowledgments

The authors would like to thank the following for funding this study: the VR-research links involving the Swedish and South African Research Foundation, the Swedish International Development Cooperation Agency (SIDA) as well as the EU-FIPSE that financed the Global Education and Developmental Studies (GEDS).

#### Declaration of interest

The authors report no conflicts of interest.

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