

# **Human rights of children with intellectual disabilities: comparing self-ratings and proxy ratings**

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## **Abstract**

**Background:** A child rights-based approach to research articulates well with Article 12 of the United Nations Convention on the Rights of the Child (CRC) and highlights the importance and value of including children's own views about aspects that concern them. The aim of this study is to compare children with intellectual disability's own ratings (as self-raters) to those of their primary caregivers (as proxy raters) regarding human rights of children. The study also aims to establish whether there is an inter-rater agreement between the self-raters and proxy raters concerning Maslow's hierarchy of needs.

**Method:** This study is nested in a larger study examining the human rights of children with intellectual disability in South Africa. In total, 162 children with intellectual disability from 11 schools across three provinces and their primary caregivers participated by answering parts of a *Children's Rights Questionnaire* (CRQ) developed by the researchers based on the United Nation's CRC. We compared the answers for six questions in the questionnaire that were addressed to self-raters (children) and proxy raters (primary caregivers) in the same way.

**Results:** Questions regarding basic needs such as access to clean water or whether the child had food to eat at home were answered similarly by self-raters and proxy raters. Larger differences were found when self-raters and proxy raters were asked about whether the child had things or friends to play with at home. Socioeconomic variables seemed to affect whether self-raters and proxy raters answered similarly.

**Conclusion:** The results underscore the importance of promoting children's rights to express themselves by considering the opinions of both the children as self-raters and their primary caregivers as proxy raters – not only the latter. The results indicate that it is especially important to include children's own voices when more complex needs are surveyed. Agreement between self- and proxy ratings could be affected by socioeconomic circumstances.

Key words: Childrens' Rights, Childhood Disability, Intellectual Disability, Proxy Ratings, Self-report

## Introduction

Children as social, economic and political stakeholders represent a majority of the population in most African countries (Terenzio 2011) and many grow up in poverty. To obtain a broader understanding of children in poverty settings, their own voices should be heard – otherwise our understanding of aspects that directly affect children (e.g. health, welfare, rights) will be incomplete (Irwin and Johnson 2005, Woodgate 2001). The United Nations Convention on the Rights of the Child (CRC) (Unicef 1989) is one of several international treaties that embed children's rights. According to the CRC, children's right to participation and their own views are considered fundamental in all implementation aspects of the CRC (Unicef 1989) (Viviers 2010) (Hodgkin and Newell 2007) (Badham 1999). Article 12 of the CRC (Unicef 1989) states that children should have the right to form their own views and express them freely and in accordance with their maturity and age. However, surveys investigating the needs of children with disabilities in low and middle income (LAMI) countries rely almost exclusively on proxy ratings from persons such as parents, relatives or other support persons (Lyngegård *et al.* 2013). Children with intellectual disabilities (ID) are a particularly vulnerable group for voicing their own opinions since they are often dependent on others – both to express themselves and to have their needs met (Oosterhoorn and Kendrick 2001). Intellectual disabilities occur when a person experiences significant limitations in intellectual functioning and adaptive behaviours, both of which must have originated before the age of eighteen (Schalock *et al.* 2010). There are very few studies in which children with ID are asked directly to give their opinion.

The focus of this study, conducted in South Africa, is to add evidence that demonstrates why children's own views are fundamental to their rights. This was done by drawing a comparison between the own ratings (self-rating) of children with ID regarding six human rights aspects that concern them and the responses of their primary caregivers (as proxy raters) on these same questions.

The reliance on proxy persons such as family members or support workers gives rise to questions about the degree to which proxy persons actually reflect the personal perception of the person with ID (Claes *et al.* 2012) about support needs (Claes *et al.* 2009) and life satisfaction (Schwartz and Rabinovitz 2003). Several studies of quality of life (QoL) and everyday functioning in adults with ID show that both self-reports and proxy ratings are methodologically reliable and indicate a considerable concordance in terms of correlations between self-reports and proxy ratings, but a variation in the perceived level of QoL and

functioning (Claes *et al.* 2012); (Perry and Felce 2002) (Schmidt *et al.* 2010). However, although self-ratings and proxy ratings are both valid, they are not interchangeable (Claes *et al.* 2012) as self-ratings and proxy ratings may capture different but overlapping aspects of the individual's life experiences and needs (Arvidsson 2013); (Claes *et al.* 2012); (Tassé *et al.* 2012) and thus also of whether children's rights are fulfilled or not.

The articles of the CRC (Unicef 1989) can be mapped into Maslow's hierarchy of needs (1943) as a fulfilment of rights imply that needs are met. Researchers such as Prince and Howard (2002) have used this hierarchy as a framework for investigating the needs of children in LAMI countries based on proxy ratings. A need is defined as something essential for survival. Maslow's hierarchy of needs comprises five levels, starting with physiological needs (level 1), safety needs (level 2), love and belonging needs (level 3), self-esteem needs (level 4), and self-actualisation needs (level 5). Human rights are seen as basic requirements for human dignity and individual freedom and they are aimed at protecting what are considered important characteristics of human beings (Ward and Stewart 2008). Since each of Maslow's five levels involves implicit rights, his hierarchy of needs provides a valuable framework for thinking about human rights and serves as a useful basis for understanding what to investigate. For instance, in poverty settings the focus is on more basic needs, i.e. the right to food, water and family because they dominate people's thoughts. However, in his original work, Maslow (1943) explains that while most people must fulfil lower-level needs before advancing to a higher level (e.g. physiological needs precede safety needs), this is not true of every individual. It is probably easier for outsiders to rate the basic needs of the individual because they are observable, while higher-order needs are based on perceptions and hence more difficult for others to gauge. According to Arvidsson *et al.* (2013) it may be difficult for proxy persons to have sufficient knowledge on a person's participation in activities that are not performed often or not considered important by the proxy person. Children's own ratings are therefore necessary to obtain reliable ratings of their own higher-order needs, such as the right to be heard.

In a systematic review to investigate generic and special needs of children with disabilities in LAMI countries, Lyngnegård *et al.* (2013) found only one paper that presented the children's own opinions. They also found that the basic level of needs (level 1) as described by Maslow (1943) was more frequently researched, whereas higher-order needs such as self-fulfilment (level 5) were seldom investigated (Lyngnegård *et al.* 2013). Hardly any comparisons are available of self-ratings and proxy ratings concerning needs and rights fulfilment on different levels for children with ID.

From a child rights perspective it is thus essential to ask children about their own experiences and perceptions. Hence the aim of our study was to obtain a broader understanding of how children with ID rate their human rights (self-rated needs) compared to ratings made by their primary caregivers (proxy rated needs). Additionally, we also tried to establish whether there was inter-rater agreement between the self-raters (children) and proxy raters (primary caregivers) in terms of those needs expressed in Maslow's hierarchy of needs.

## **Method**

This study was nested in a larger study that examined the human rights of children with intellectual disability in South Africa (Donohue *et al.* 2013). The researchers developed a questionnaire, the *Children's Rights Questionnaire* (CRQ), based on the United Nations Convention on the Rights of the Child (Unicef 1989). It referred particularly to Article 23, stating that children with disabilities have the right to a decent life, access to healthcare and rehabilitation, educational and vocational services. In the comparison between self-raters (children) and proxy raters (primary caregivers), we focused on the six questions in the questionnaire that were addressed to self-raters (children) and proxy raters (primary caregivers) in the same way. The questionnaire also contained a section on demographic characteristics such as income, education, age and household size. Descriptive items related to the child were asked, for example, whether the child had a birth certificate, whether the child experienced physical and/or motor delays and whether the child's disability had been apparent at birth.

The consent letter and questionnaire used in the study were developed in English and translated into Afrikaans, Xitsonga or isiZulu, depending on the language of instruction in the schools that the participants attended. For this translation, a blind back-translation process (Bornman *et al.* 2010) was used to establish construct validity. Two different expert panels of professionals with experience in the field were asked to comment on the items and the questionnaire was subsequently revised based on their suggestions (Erasmus 2012). A pilot study was next conducted to further refine the questionnaire itself and the methods for data collection. The questionnaire used a 4-point Likert scale with two positive options (4 = always and 3 = sometimes) and two negative options (2 = seldom and 1 = never) for each statement. According to (Babbie 2013), designing a Likert scale with a balanced keying (an equal number of positive and negative statements) prevents the problem of participant bias, since agreement on positive statements balances out agreements on negative key statements.

Ethical approval for conducting this study was obtained from the relevant higher education institution. Formal permission also was obtained from the Gauteng, Limpopo and KwaZulu-Natal Departments of Education, the school principals and teachers involved, and consent was obtained from the children's primary caregivers. Although the same questionnaire (see above) was used for both the child participants (self-raters) and the primary caregivers (proxy raters), the method used to collect the data differed.

In to decrease the potential confounding effects of language comprehension and/or language production commonly associated with intellectual disability, the self-raters completed the questions by using the Talking Mats™ (Murphy 1998) format. In this format, an A3 mat was presented to the children with four images along the top representing the four-point scale discussed earlier. Each item in the questionnaire was represented by a laminated card depicting a key word and an associated visual image (a Picture Communication Symbol), e.g. the graphic symbol for 'toys' depicted generic toys that children would typically be familiar with, such as ball, car and doll. The children were handed the cards one by one and asked to place them on the mat under the appropriate point on the scale. This was done by qualified speech-language therapists or in some cases speech therapy assistants working under the supervision of a therapist. To ensure that the children understood the response method, three training items and three trial items were presented. Trial items had an expected response, e.g. *How often do you play with live snakes?* With each item, children were asked to first consider it as a yes/no choice and then, depending on their answer, to judge it as 'yes, always', 'yes, sometimes', 'no, never' or 'not really'. As explained earlier, the primary caregivers (proxy raters) received the questionnaire via the children's teachers and they completed it independently at home. The children were brought individually to a quiet testing place. They were informed that everything they said would be confidential, and that they could choose whether they wanted to participate. They were also informed that they could stop at any time, without any negative consequences. For those who assented, the questionnaire was administered during individual sessions by a member of the research team in South Africa.

### **Sampling and participants**

A multi-phase sampling procedure starting with the province, followed by the special schools and finally the children, was used. The per capita income per province was used to purposively sample the province. Gauteng has the highest average annual income per capita (approximately USD\$9,681), whilst KwaZulu-Natal (approximately USD\$4,767) and

Limpopo (approximately USD\$4,259) have two of the lowest. Hereafter, school districts were identified based on the National List of Special Schools (RSA, 2010) that focuses on districts with government-funded special schools for children with intellectual disability. Thirteen school districts in Gauteng, 12 in KwaZulu-Natal, and five in Limpopo met the criteria. To maintain comparable ratios between districts within provinces, two school districts in Gauteng, two school districts in KwaZulu-Natal, and one in Limpopo were randomly selected for potential participation. Within Gauteng, seven of the potential nine school principals in the various districts provided consent for the research, whereas three of the potential six principals in KwaZulu-Natal consented and one of the potential two principals from Limpopo provided consent. Thus, a total of 11 school principals across three provinces consented to participate in this research.

The final step of the sampling procedure entailed the sampling of children. Teachers at the included schools were given a standard set of instructions to identify – for potential participation – children in their classroom who were between eight and 14 years old, who experienced no hearing loss or uncorrected sight problems, and who used either English, Afrikaans, isiZulu or Xitsonga (the four languages included in the study) as home language. Consent forms and questionnaires were distributed to primary caregivers, in their home language, via the classroom teachers. A total of 234 children received consent from their primary caregivers, but two children declined to participate. The remaining 232 children were presented with both training and trial items for the questionnaire. Twelve children failed the trial items and were thus assessed as unable to complete the research procedure. A total of 220 children and primary caregivers eventually participated, but altogether 58 were excluded from the analysis for different reasons (their children lived in a group home; the primary caregivers did not complete the biographical section of the questionnaire; the data was incomplete in some way). A final sample of 162 child participants (self-raters) and 162 primary caregivers (proxy raters) was eventually obtained. The primary caregivers' relationship to the child was found to be as follows: 59,9% mothers, 17,5% fathers and 22,6% others (e.g. grandmothers or siblings).

### ***Data analysis***

Descriptive statistics with range, mean and SD was reported. Kappa coefficients were calculated using the more robust AC1 statistics introduced by Gwet (2002) for inter-rater reliability. Gwet's AC1 was used due to the skewed distribution in the material, and for the

interpretation of results 1 was taken to stand for good agreement and 0 for agreement no better than chance (Wongpakaran *et al.* 2013).

Logistic regression was performed to investigate whether socioeconomic variables (South Africa Income Tax Act) influenced self-raters' and proxy raters' decision to give the same answer to the questions. A 4-item risk index was created for socioeconomic variables, which included household income, education, work status, and relationship status. Participants received a point for every high-risk socioeconomic factor they were experiencing: 1) their annual household income had to be less than R60 000 (approximately USD\$7,500) (in terms of the South African Income Tax Act, families earning less than this amount are exempt from paying personal income tax); 2) the highest educational level reached by their primary caregivers had to be grade 10 or below; 3) they had to be unemployed, and 4) their caregiver had to be neither a marriage partner nor someone with whom they were in a constant relationship. The frequencies are displayed in Table 1.

**Table 1:** Description of participants according to socio-economic risk factors

Risk items	High risk	Low Risk
Familial income per annum (R60,000 is about 5 500 US Dollar)	R60,000 or less <i>n</i> =104 64,2%	Above R60,000 <i>n</i> = 58 35,8%
Highest education of primary caregiver	Grade 10 or less <i>n</i> =74 45.7%	Grade 10 or higher <i>n</i> = 88 54.3%
Work status of primary caregiver	Unemployed <i>n</i> = 65 40.1%	Employed full-time or part-time <i>n</i> = 97 59,9%
Primary caregiver relationship status	Married or in constant relationship <i>n</i> =104 64.2%	Single parent <i>n</i> = 58 35.8%

## Results

The average age of the self-raters was 11 years. The male:female ratio was exactly 2:1 with 108 male participants (67%) and 54 females (33%). As expected, almost all the children had a birth certificate (99%), as this was needed for school enrolment. In all probability, the 1% without a certificate were in the process of obtaining it. It was reported that 82% of them



had access to medical services (e.g. community clinics, hospitals, nurses or doctors). Nonetheless, access to medical services was hampered by issues such as the critical shortage of professionals (doctors, nurses, rehabilitation professionals), large distances to medical facilities, transport difficulties, financial constraints, the high rate of HIV/Aids and its effect on the primary health care system, and the unavailability of essential medicine (Voice\_of\_America 2012). The home languages of participants were isiZulu (29%), Afrikaans (25%), English (23%) and Xitsonga (23%), and 61% of the children had their impairment(s) identified at birth. The age of primary caregivers (proxy raters) ranged from 22 to 67 years old, with a mean age of 39 years.

Whereas the questions on clean water and food (Maslow level 1) were answered similarly by self-raters and proxy raters, the responses to the question about having someone

**Table 2:** Comparison of self-ratings (children) and proxy ratings (primary caregivers) (N=162) for six items related to Maslow's hierarchy of needs

Item	Self-rating		Proxy rating		AC1	Level of Maslow's hierarchy of needs
	Mean (SD)	Range Min-max	Mean (SD)	Range Min-max		
1. Do you have clean water to drink at home?	3.82 (0.40)	1-4	3.98 (0.14)	3-4	0.790	1
2. Do you have food to eat at home?	3.86 (0.38)	2-4	3.84 (0.50)	1-4	0.766	1
3. Do you have things to play with at home?	3.14 (1.19)	1-4	3.28 (1.14)	1-4	0.401	2
4. Do you have your own bed to sleep in at home?	3.74 (1.05)	1-4	3.44 (1.13)	1-4	0.648	2
5. Is there someone who cares for you and protects at home?	3.80 (0.49)	1-4	3.91 (0.36)	2-4	0.748	2 & 3
6. Do you have friends to play with at home?	3.51 (0.93)	1-4	3.38 (0.93)	1-4	0.435	2 & 3

to care for and protect the child at home (level 2 and 3) differed. The largest differences in the answers were in the ratings concerning things to play with (level 2) and whether the children had friends at home (levels 2 and 3). (See Table 2.)

In the logistic regression, socioeconomic variables were used as independent variables. The results showed that when the primary caregiver had been educated for less than 10 years, the self-raters and proxy raters were less likely to give the same answer to the question about water (level 1). Also, when the primary caregiver was unemployed or the total income of the household was less than R60 000 per annum, the self-raters and proxy raters were less likely to give similar answers to the question about whether they had things to play with (level 2). In cases where the primary caregiver was unemployed, the self-raters and proxy raters were also less likely to give the same answer to the question about whether someone cared for and protected the child at home (levels 2 and 3). (See Table 3.)

**Table 3:** The impact of socio-economic variables on self-ratings and proxy ratings (N=162)

Independent variable	1. Clean water to drink at home? (level 1)			2. Food to eat at home? (level 2)		
	P	AOR	95% CI	P	AOR	95% CI
Single primary caregiver	0.835	1.095	0.46-2.59	0.827	0.916	0.42-2.00
Unemployed	0.299	0.608	0.24-1.56	0.435	0.394	0.60-3.21
Educated for less than 10 years	<b>0.046</b>	2.824	1.02-7.83	0.601	1.264	0.52-3.04
Total income of household less than R60 000 per annum	0.625	0.762	0.16-2.27	0.544	1.360	0.50-3.68

  

Independent variable	3. Things to play with at home? (level 2)			4. Own bed to sleep in at home? (level 2)		
	P	AOR	95% CI	P	AOR	95% CI
Single primary caregiver	0.655	1.175	0.58-2.39	0.477	1.295	0.64-2.64
Unemployed	<b>0.020</b>	0.393	0.18-0.86	0.905	0.954	0.44-2.06
Educated for less than 10 years	0.200	0.585	0.26-1.33	0.431	1.380	0.62-3.08
Total income of household less than R60 000 per annum	<b>0.000</b>	6.520	2.260-16.37	0.209	1.790	0.72-4.44

  

Independent variable	5. Someone to care for the child and protect the child at home? (levels 2 & 3)			6. Friends to play with at home? (levels 2 & 3)		
	P	AOR	95% CI	P	AOR	95% CI
Single primary caregiver	0.691	1.175	0.53-2.61	0.891	1.049	0.53-2.07
Unemployed	<b>0.023</b>	0.351	0.14-0.86	0.197	1.635	0.77-3.45
Educated for less than 10 years	0.824	1.105	0.46-2.68	0.228	0.626	0.29-1.34
Total income of household less than R60 000 per annum	0.379	1.523	0.60-3.39	0.146	0.546	0.24-1.23

## Discussion

In legal terms, South Africa subscribes to a dualistic system. This implies that international conventions such as the CRC (ratified on 16 June 1995) and the Convention on the Rights of Persons with Disabilities (ratified on 30 November 2007) have been

domesticated to reflect in all other South African laws relevant to children. However, despite this ratification, the incorporation of these conventions into domestic law is still in progress. Lundy (2007) provides a model for conceptualising Article 12 in the CRC by reflecting on the following four elements: *space* (children should have the opportunity to speak their opinion); *voice* (children must be assisted to give their opinion); *audience* (the children's opinions must be listened to), and *influence* (the children's opinions should be acted upon as appropriate). By considering these four elements, children's rights can be better addressed. Our study has shown that although proxy raters can give important information on the level of compliance with the rights of children with ID, a more comprehensive understanding of the child's self-rating should also be obtained, thus bringing it in line with Article 12 of the CRC. More complex needs (i.e. higher needs in Maslow's hierarchy) and thus more complex rights such as a right to having someone to play with (art 31) have lower inter-rater agreement when the children's ratings and the proxy ratings are compared.

In LAMI countries, proxy ratings are often used in studies on children with disabilities to research basic needs such as food and water (Lyngnegård *et al.* 2013) and our study confirms that lower-level basic needs can indeed be surveyed using proxy ratings. However, the results indicate that it is especially important to consider the own voices of children with disabilities in LAMI countries when their more complex higher-order needs are surveyed. The focus on basic needs and proxy ratings in earlier studies may underestimate children's own experiences concerning environmental needs related to rights, such as the right to have their voices heard, the right to self-fulfilment and the right to education, even in poverty settings.

However, the level of agreement between primary caregivers and children depends not only on the questions posed, but also on the circumstances in which the respondents live. For example the results might suggest that lower socioeconomic status is linked to the discrepancies in question regarding access to clean water.

The responses of the children and primary caregivers to three out of six investigated questions correlated with socioeconomic factors, and higher agreement occurred when the primary caregivers were in a better socioeconomic situation. This trend seemed to be independent of whether a basic or complex need was rated. One explanation might be that primary caregivers in a worse socioeconomic situation had to give priority to other family tasks rather than spend time with their children, and thus they knew less about their children's everyday experiences. The reality for many primary caregivers who have a child with a

disability is that they are often single parents (mostly female), unemployed and therefore staying at home taking care of the child (Anderson *et al.* 2007). Using the same data as in this study, Donohue *et al.* (2014) report that the level of children's self-rated needs was related to a risk index based on the number of environmental risks experienced by the child (e.g. household size, level of income). Although only broad trends are clear from this study (since only six questions were analysed for inter-rater agreement), the correlation between child-proxy agreement and socioeconomic factors indicates that it is essential to ask children in poverty settings directly and personally about their own experiences.

### **Conclusion**

This paper presents results that underscore the importance of considering the opinions of both the children and their primary caregivers. In previous studies, proxy ratings were typically used for surveying the living conditions of children with ID. The current study highlights the importance of promoting children's rights to express their own views when their more complex needs are surveyed. The results also suggest that agreement between the answers of children and their primary caregivers depends on their socioeconomic circumstances and that in poverty settings, children's own voices are even more important. This apparent association should be further explored in future studies using a mixed method study. Grover (2004) states that research that gives a voice to children allows the children to be subjects and not mere objects in research. The inclusion of children with disabilities' own opinions makes an important positive contribution to research that aims to improve the rights of children with disabilities – in line with the recommendations of the United Nations Convention in the Rights of the Child.

### **Limitations of the study**

The research design employed only allows for the recognition of associations and hence results should be interpreted with caution. Only children who attended the 11 special schools for children with ID in South Africa were included in our study. Many South African children with disabilities do not even attend school and often these children are hidden and excluded from basic rights (Saloojee *et al.* 2007). Furthermore, only 6 questions were assessed and correlated with socio-economic factors. The results of our study revealed only small differences when the ratings of children and primary caregivers were compared, and may have been different, had the hidden children's primary caregivers been included.

## Recommendations for further study

Future studies need to include a larger number of items that represent both basic and complex needs, and they need to be phrased identically for children and primary caregivers. In addition, a wider span of socioeconomic circumstances among primary caregivers in poverty settings needs to be related to parent-child inter-rater agreement, and if older children are included, needs that reflect levels 4 and 5 in Maslow's hierarchy should also be included. Other methods to triangulate the data could be direct observation in their home setting. No intervention out of the result have been done so far, however the results could be used in policy development to justify that the voices of children with intellectual disabilities should be heard and addressed. Follow up studies are planned in Australia and Botswana with a refined questionnaire. Finally, qualitative studies exploring the views of children on specific rights issues in depth would be of great interest.

### Key Messages

- It is crucial to include the perspectives of children with intellectual disabilities because they rate certain needs, particularly higher-order needs (for example loving and belonging in Maslow's hierarchy of needs) differently than proxies. Thus, using a child rights approach leads to more accurate findings and promotes the right to participation of children with intellectual disability (socially just).
- Proxy ratings can be used for lower levels of needs.
- Children self-raters and primary caregiver proxy raters may answer questions on higher level needs differently according to socioeconomic factors.

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