

Afrikaans-speaking parents' perceptions of the rights of their children with mild to moderate intellectual disabilities: A descriptive investigation

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Abstract

This study aimed to describe the perceptions of Afrikaans-speaking parents regarding the human rights, as defined by the UNCRC, of their children with mild to moderate intellectual disabilities, aged between 8.0 and 14.11 (years.months). The underlying premise is that the UNCRC defines the rights of children, whereas the ICF-CY can provide the framework for documenting a deprivation of rights and the conditions under which those rights can be realised (Simeonsson, 2006). Forty-seven Afrikaans-speaking parents completed a custom designed survey. The results of the closed-ended questions indicated that most parents felt that their children had rights and that these rights were met. A theme analysis performed on the open-ended questions revealed that parents were mostly concerned about their children's rights pertaining to school education and safety. These rights were discussed in terms of the UNCRC articles and linked to environmental codes of the ICF-CY. Finally the limitations and implications of the study are discussed and recommendations are made.

Keywords

Children's rights, human rights, intellectual disability, International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY), parents, United Nation's Convention on the Rights of the Child (CRC)

Introduction

Realising the basic needs of children and providing them with comprehensive care are among the ethical principles known as human rights (Van Bueren, 1998). Human rights refer to those rights that are considered universal to humanity, regardless of citizenship, residency status, ethnicity, gender, disability or other considerations (Sen, 2004).

Many international governing bodies such as the United Nations (UN) and the World Health Organization (WHO) have advocated for universal human rights. According to the most widely accepted human rights convention in history, the United Nations Convention on the Rights of Children (UNCRC), needs become rights when they are recognised as absolutely necessary for protection and quality of life (United Nations General Assembly 1990).

The International Classification of Functioning, Disability and Health (ICF) and the ICF-CY, its extension for children and youth (WHO, 2001, 2007), were formulated to provide a universal conceptual framework for the classification of health and health-related domains. The ICF-CY and the UNCRC complement each other. The UNCRC defines the rights of children, whereas the ICF-CY provides the framework for documenting a deprivation of rights and the conditions under which those rights can be realised (Simeonsson, 2006). The ICF-CY describes the situation of each individual within the context of environmental and personal factors, rather than classifying the individual according to his/her health or health-related conditions only (UNESCO, 2006). As such, the ICF-CY includes three individual dimensions: body functions and structures; activities and participation; as well as two contextual dimensions, namely personal factors and environmental factors (WHO, 2007).

Environmental factors add information about how the context affects a child's functioning (WHO, 2007) and is the focus of this paper. These environmental factors, which include physical barriers, attitudes or social policies, can act as either supports or barriers to participation for children with disabilities. The ICF-CY can thus document the child's limitations and environmental barriers, thereby providing evidence for the right to protection, care and access (Simeonsson, 2006). The ICF-CY may provide the basis for the explicit documentation of rights (Carlhed, Björck-Åkesson & Granlund, 2003) in other words it may be a source of evidence to identify, in particular, the lack of rights at the level of the individual child (Simeonsson, 2006).

All over the world, children and especially children with disabilities and their parents are challenged by significant barriers to their human rights (Gobrial, 2012). In the past they have often been denied their human rights (Wart & Stewart, 2008). Intellectual disability is a pervasive and lifelong condition that not only affects the individual, but also places a burden on families and the community at large (Olsson & Hwang, 2003). It is characterised by

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significant limitations in both intellectual functioning and adaptive behaviour (as expressed in conceptual, social and practical adaptive skills) which originates before the age of 18 years (Schalock et al., 2007). Almost 3% of the world population (WHO, 2001) and an estimated 3.6% of the South African population has some form of intellectual disability (Christianson et al., 2002).

Recent studies show an increasing concern about the way in which children with intellectual disability have been treated, together with a heightened awareness of children's rights (Peens & Louw, 2000; Burke, 2005). Burke (2005) also argues that families of children with disabilities have limited resources available to them; therefore, it is essential to consider availability against that which is a right. The views of parents are also important in understanding children's rights since they are in a favourable position to either fulfil or restrict their children's nurturance or self-determination rights (Cherney & Shing, 2008; Day et al., 2006; Ruck et al., 2002). Parents play a crucial role in the lives of their children and are often the best advocates for ensuring that their children's rights are recognised (Ruck et al., 2002) and that those mandated, are met (Austin, 2000).

The main aim of this research was to describe the perceptions of Afrikaans-speaking parents regarding the human rights of their children with mild to moderate intellectual disabilities (Erasmus, 2012). This research forms part of a larger research project that compares parental and child perspectives concerning the rights of children with mild to moderate intellectual disabilities (Donohue et al., 2014; Donohue et al., in press).

Methods

Design

This research used a quantitative descriptive survey design with a custom-designed survey instrument (Donohue et al., 2014).

Participants

One Afrikaans-medium special school that serves children with mild to moderate intellectual disabilities in a low socioeconomic neighbourhood was selected. Eighty-six parents at the school met the four selection criteria, namely

- parenting a child between the ages of 8.0 and 14.11 years; months

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- using Afrikaans as home language;
- being literate and able to independently complete the survey instrument; and
- having provided consent.

All 86 potential participants received consent letters attached to the survey instrument. Seven participants did not return the instruments. Of the 79 completed survey instruments, 30 were excluded due to incompleteness, and two participants were excluded as they were parenting children in a group home. The participant descriptives are shown in Table 1.

Survey instrument

A survey instrument was custom-developed for this research and subsequently piloted (Donohue et al., in press). It comprised three sections:

- A. Biographical information about the parents and their children
- B. Information from the Ten Questions Questionnaire screening tool (TQQ) (Durkin, 2001)
- C. 14 closed-ended questions related to the needs and rights of children with disabilities, and linked to UNCRC articles and ICF-CY environmental codes

These questions were rated on a 4-point Likert-type scale (1= Never (“nooit”); 2= Seldom (“selde”); 3= Sometimes (“soms”); 4= Always (“altyd”). Perceptions of positively worded statements were tallied from 4 (Always) to 1 (Never) and negatively worded statements were reverse scored. This implies that a high score represented a positive perception and a low score a negative perception.

A Yes/No question followed the close-ended questions, and probed participants’ perception of whether they perceived their children with disabilities as having rights. If participants answered “yes”, they were requested to list and prioritise these rights.

The survey instrument was developed in English (source language) and independently translated into Afrikaans (the target language) by three translators, using a blind-back translation procedure (Bornman et al., 2010).

Data collection procedures

Ethical approval was obtained from the relevant higher education facility, as well as from the local government authority and school principal. The principal introduced the first author to the teachers who assisted in identifying possible participants’ children. The consent letters and survey instrument were sent to parents via their children. The teacher wrote a short

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note in each child's homework book in which they were requested to complete the forms. Children who returned the forms received a small packet of sweets, irrespective of whether the parents had given consent. A week later a reminder was sent. The survey instruments were collected three weeks after distribution.

Reliability

An independent peer coded 40% of the data in order to determine consistency of coding. The reliability of the data was found to be 99.3%.

Deductive coding was used for the open-ended question, with the 22 articles of the UNCRC as the basis. A five-person expert panel who had experience in the disability field and who were familiar with the UNCRC were provided with background information on the aims of the study as well as detailed written information on the different articles of the UNCRC. Thereafter they were requested to link the rights mentioned by the parents to a specific article of the UNCRC in order to enhance the construct validity (Erasmus, 2013). Once the items had been linked to the appropriate UNCRC article, and each panel member had linked the items to the articles, the different answers were discussed until consensus was reached. Next, a researcher with extensive experience in the ICF-CY worked with the authors to award ICF-CY environmental codes to these rights, according to the rules suggested by Cieza et al, 2005.

Results

The results of the biographical information (Section A) were presented in respect of the participants and their children. Although mostly mothers (66%) completed the survey there were also nine fathers (19%) and six "other primary caregivers" (13%) which included grandparents. Most of the participants (55%) had limited education (grade ten or less), 21% had completed high school (grade 12), while 9% had a basic qualification and five a postgraduate qualification (10%). Most (49%) were married, with 19% in either a committed relationship, or with other living arrangements or acting as single parents. 55% of the participants had the annual family income of R60 000 or less, which implied that they did not pay personal income tax and were thus regarded as being "poor". Most of the children with disability were boys (53%) almost all had access to birth certificates (96%); most had access to public medical services (67%) and most were acquired disabilities (57%).

Since Section B of the survey instrument was based on the TQQ (Durkin, 2001), it contained disability-specific questions. The results showed that 91.84% of parents thought that their children understood them when they instructed them to do something, and 57.45% indicated that their children had learned to do things similar to typically developing peers. According to the parents' perceptions, only 2.04% of the children had difficulty with motor function, although 54.76% reported that their children had had serious developmental delays with regard to sitting, standing or walking. Furthermore, 89.80% of parents believed that their children could speak and say recognisable words. Despite this, 39.58% of parents reported that their children's speech was different from typically developing peers and not clear enough to be understood by persons outside of the immediate family circle. A small percentage of parents (6.12%) indicated that their children sometimes had epileptic seizures.

Section C dealt with the participants responses to the closed-ended questions and the results are shown in Table 1. Parents indicated that their children *Always* had clean water to drink (100%) and that there was *Always* someone to take care of their children at home. They also indicated that in most cases (93.88%) their children *Always* had their own bed to sleep in and *Always* had food to eat (91.67%). However, parents had varying opinions regarding their child's suitable placement in school and regarding friends to play with at home. The question regarding friends yielded the smallest number of *Always* responses (53.06%). Despite that, 91.84% of the participants indicated that their children *Always* had toys to play with at home.

Regarding the question of whether they thought their children had rights, 90.70% answered "Yes" while six participants did not answer this question. The 43 participants mentioned a total of 187 rights. Each right was subsequently linked through deductive coding to the articles of the UNCRC and to the environmental component of the ICF-CY as discussed earlier.

Table 2 shows that of the 28 rights mentioned, the right to education (12.37%) (Article 23,28,29) and the right to safety (11.83%) (Article 6,9,19,24,27) was mentioned most frequently. Other rights included the right to religious freedom, the right to information, the right to affordable transport to school and the right to electricity, and these represented 14, 28,27of the UNCRC articles. However, since parents answered this question in an open-ended format, it may be extrapolated that they were indeed concerned enough about these rights to mention them.

Table 1: Parental perceptions of specific children's rights (n=47)

		Always	Sometimes	Seldom	Never
Question	Does your child have clean water to drink at home?	100%	-	-	-
UNCRC	6; 24; 27				
ICF-CY	e110; e310; e315				
Question	Does your child have food to eat at home?	91.67%	6.25%	2.08%	-
UNCRC	6; 24; 27				
ICF-CY	e110; e310; e315				
Question	Does your child have his/her own bed to sleep in at home?	93.88%	-	-	6.12%
UNCRC	27				
ICF-CY	e115				
Question	Does your child have things to play with at home?	91.84%	6.12%	2.04%	-
UNCRC	31				
ICF-CY	e115				
Question	Is there someone who takes care of your child at home?	100%	-	-	-
UNCRC	24; 27				
ICF-CY	e310/e410; e575				
Question	Does your child have friends to play with at home?	53.06%	36.73%	4.08%	6.12%
UNCRC	15; 31				
ICF-CY	e320/e420; e325/e425				
Question	Do you think your child is suitably placed in this school?	78.72%	6.38%	8.51%	6.38%
UNCRC	23; 28; 29				
ICF-CY	e583; e585; e586				

The 28 rights mentioned resulted in 915 ICF-CY linkages to 36 second-level environmental codes. A summary of the linkages and environmental codes is shown in Table 3.

Table 3 shows that four of the possible five environmental codes were represented, albeit with different frequencies. This table also reveals that parents valued *attitudes* (e4) as most important (40%). They mentioned *support and relationships* (e3), as well as *services, systems and policies* (e5) 28% and 22% of the time respectively, and referred to *products and technology* with the lowest frequency (10%). The code *natural environment and human-made changes to environment* was not mentioned.

Table 2: Parental perceptions on children's rights (n=47)

Number	Rights mentioned and linked to UNCRC (articles) and ICF-CY environmental codes (e)	Percentage
1 UNCRC ICF-CY	The right to school education 23, 28, 29 e583; e585; e586	12.37%
2 UNCRC ICF-CY	The right to safety (including the following places / people) 6, 9, 19, 24, 27 e150; e155; e310/e410; e315/e415; e320/e420; e325/425; e330/e430; e345/e445; e545; e570	11.83 %
3 UNCRC ICF-CY	The right to be taken care of by parents 24, 27 e310/e410; e315/e415; e575	6.45%
4 UNCRC ICF-CY	The right to love and understanding 9, 27 e310; e410	5.91%
5 UNCRC ICF-CY	The right of access to medical services 24 e110; e570; e580	5.38%
6 UNCRC ICF-CY	The right to freedom of speech 12, 13 e410; e430; e595	5.38%
7 UNCRC ICF-CY	The right to be respected by family; by friends; by strangers; by teachers; by the community 12, 29 e410; e415; e420; e425; e430; e440; e445	5.38%
8 UNCRC ICF-CY	The right as an individual 8 e595	4.83%
9 UNCRC ICF-CY	The right to freedom 12, 13, 14, 15 e595	4.83%
10 UNCRC ICF-CY	The right to food 6, 24, 27 e110; e310; e315	3.76%
11 UNCRC ICF-CY	The right against physical abuse 19, 32, 34, 39 e310; e315/e415; e320/e420; 325/e425; e330/e430; e340/e440	3.76%
12 UNCRC ICF-CY	The right to be accepted 2, 30 e410; e415; e420; e425; e430; e440; e450	3.76%
13 UNCRC ICF-CY	The right to a family life 9, 18 e310; e315: e310; e315:	3.23%
14 UNCRC	The right to housing 27	2.69%

ICF-CY	e155; e525	
15 UNCRC ICF-CY	The right to clothes 27 e115	2.69%
16 UNCRC ICF-CY	The right to be treated fairly 2 e410; e420; e425; e430; e440; e450	2.15%
17 UNCRC ICF-CY	The right to meet with groups/ friends 15, 31 e320/e420; e325/e425	2.15%
18 UNCRC ICF-CY	The right to play/toys 31 e115	2.15%
19 UNCRC ICF-CY	The right to clean/safe water 6, 24, 27 e110; e310; e315	2.15%
20 UNCRC ICF-CY	The right to have rights 5 e595	2.15%
21 UNCRC ICF-CY	The right to an acceptable standard of living – own bed 27 e115	1.61%
22 UNCRC ICF-CY	The right to special support and health care/therapeutic services 23, 24 e580	1.08%
23 UNCRC ICF-CY	The right to be educated in home language 28 e585	1.08%
24 UNCRC ICF-CY	The right to hygiene/best health care 24 e150; e155; e510	1.08%
25 UNCRC ICF-CY	The right to religious freedom 14 e595	0.54%
26 UNCRC ICF-CY	The right to information 13, 17 e125; e130; e535; e560	0.54%
27 UNCRC ICF-CY	The right to affordable transport to school 28 e120; e310; e315; e540; e585	0.54%
28 UNCRC ICF-CY	The right to electricity/safe home 27 e510; e525; e530	0.54%

Table 3: Environmental codes used for the rights of children

<u>e1</u>	<u>e2</u>	<u>e3</u>	<u>e4</u>	<u>e5</u>
Products and technology (7 e1 codes)	Natural environment and human-made changes to environment	Support and relationships (7 e3 codes)	Attitudes (8 e4 codes)	Services, systems and policies (14 e5 codes)
89 links (10%)	0 links (0%)	253 links (28%)	377 links (40%)	196 links (22%)

Discussion

Parents mentioned *attitudes* most frequently attesting to the importance of addressing attitudes as part of human rights. Parents wanted the immediate family to show love, respect and acceptance of the child with mild to moderate intellectual disability. Parents also indicated the importance of *support and relationships*. Children with mild to moderate intellectual disabilities needed a particular level of attention when they were cared for or looked after, and parents sometimes found it difficult to ask friends and family for help in taking care of the child with special needs. The participants furthermore selected *services, systems and policies* as an important domain. It seems that parents were of the opinion that their children with mild to moderate intellectual disabilities were entitled to rights and services in schools and therefore any discrimination against them would be unacceptable. Parents wanted to be proactive and hence took the necessary steps to make sure that their child received appropriate services in his/her school. *Products and technology* were not considered that important by parents, probably because most of the children in this study did not have motor impairments, and physical accessibility might not have been such a key factor.

The results of the study evidenced that the different rights grouped and linked in terms of the ICF-CY environmental codes contributed to parents' specific perceptions of the needs and rights of their children with mild to moderate intellectual disabilities. Several factors added to the fact that parents considered certain needs as more important than others. The results from this study therefore seems to support Simeonsson (2006) who suggested that ICF-CY can document barriers in the child's environment and so provide explicit evidence for the child's right to protection, care and access. The ICF-CY may therefore also function as a standard for documenting the nature and severity of the child's disability and thereby

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formalise the child's right to protection from discrimination, abuse, neglect and denial of access (Simeonsson, 2006). It constitutes a universal reference or framework for the development of national policies, legislation and practices pertaining to the rights of children with disabilities.

Limitation of the study included the i) homogenous group of primary caregivers from ii) a specific geographical area iii) about a specified age group of children which resulted in reduced external validity of the findings. However, the results of the study suggest that the different rights can be grouped and linked with regard to the ICF-CY Environmental codes. This may potentially provide the basis for the explicit documentation of rights and the lack of rights for the individual with disabilities in future.

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