

Children's rights, measuring participation and cultural differences : an African perspective

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Researchers Conference on Children in Need of Additional Support

Science Park, Jönköping University, Sweden

28 May 2014



Aims of the presentation

- To briefly discuss the impact of culture on participation
- To link children's rights to participation & discuss the critical importance thereof for LAMI countries
- To provide a brief overview of children with disabilities in Africa
- To discuss the importance of including children's own voices in research
- To explain the research project on participation and human rights by referring to 5 studies



Participation and Culture

- Social environments & family routines are culturally embedded
 - attitudes towards children
 - what is expected from children
 - how children should behave
 - what skills should be encouraged and developed in children
- Surface adaptations vs deep structure adaptations
- Health and disability are considered “sensitive issues” - not widely discussed
- Language barriers (often not English)
- Written languages vs oral languages
- Cultural role of story telling:
 - to teach children,
 - to hand down knowledge,
 - to set the protocols for behavioural expectations
 - to outline cultural responsibilities.



Why focus on children's rights ?

- United Nation
 - Convention on the Rights of the Child (CRC)
 - Convention on the Rights of Persons with Disability (CRPD),
- Creation of enabling, inclusive environments that accommodate all individuals in their diversity.
- Focuses on most vulnerable members of society
- Migration of disability issues into the human rights arena – rights-bearers rather than as recipients of pity and charity.
- Link between poverty and disability
- African children with disability often live in dismal poverty : no clean water, no electricity, no indoor plumbing,



Why focus on children's rights ?

Most studies on non-fulfilment of children's rights in LAMI countries focus on:

- **Physiological needs** → implies that unless basic needs are fulfilled, higher order needs cannot be fulfilled.
- Have **care givers are proxy respondents** → implies that
 - children can't talk for themselves
 - care givers can provide reliable ratings on all kinds of needs
- Focus on **children without impairments** → implies that children with impairments have lower status and are less important members of society



Children with disability in Africa...

- Children with disabilities face challenges in all spheres of life [Armstrong, 2007](#)
- Children with disabilities are exposed to range of human right violations, e.g. harassment, abuse, domestic violence, community violence, war and terrorism [Mepham, 2010](#); [Sullivan 2009](#)
- Often information is not available to these children due to disability, e.g. visual impairment [African Union, 2010](#)
- Disability is often not viewed as a rights issue as people with disability are not viewed as part of the general public, but as people with special needs [Hurst , 2003](#)

Disability in South Africa

- Approx 10% of world population have some form of disability [WHO, 2005](#)
- In South Africa more than 2 million people have some form of disability
- Only 104,000 children with disabilities attend special schools
- These children have a choice of 63 special schools nationally to matriculate from.
- A further 118, 000 learners are enrolled in mainstream schools [Suleman & Hodgson, 2014](#)
- **Where are the other 500,000 children????**

Needs and Rights

- Needs and rights are closely related [Conrad, 2010](#)
- Human rights can be defined as a just and proper claim to the fulfillment of human needs with neither fear nor embarrassment [Annas, 1989](#)
- Needs become rights when they are recognized as being necessary for protection and quality of life [UNCRC, 1989](#)
- Purpose of children's rights is not to make it completely equal to adult's rights, but to guarantee child opportunities for fulfillment of human needs and to ensure protection needed by children [Farmer, 2001](#)
- Abraham Maslow's theory can provide theoretical framework for looking at needs [Maslow, 1943](#)

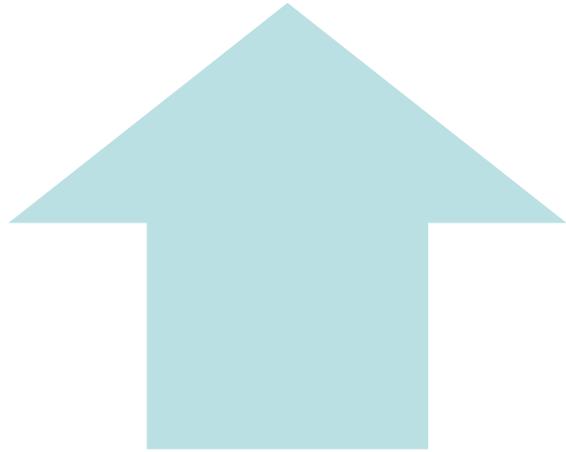
The three P's of human rights...

Alderson, 2000; Simeonsson

- **Provision rights:** rights to necessary goods and services available to the child, such as the right of access to medical services (Article 4), the right to be taken care of (Article 2 and 27), the right to be educated in one's home language (Article 28), the right to affordable transportation to school (Article 28) and the right to a safe home (Article 27)
- **Protection rights :** the right to be protected from abuse (Articles, 19 and 32) and the right to safety (Articles 6, 9 and 19).
- **Participation rights:** rights where children are conferred the right to be respected and to be an active participant in family, school and community life, provided with some action; for example, the right to be heard (Article 124) and the right to play (Article 31)

» but..... the lines are blurred....





Positive rights
(participation and
provision rights)



Negative rights
(prevention
rights)

Deprivation on rights

Simeonsson, 2008

- Constraint, limitation or barrier in child's **access to** or in his/her **encounters with physical, social or psychological environment** essential to their growth and development
- Constraint, limitation or barrier of child's **opportunities to participate** in major life roles

Progressive realization of rights

- Economic constraints may prevent all individuals from obtaining positive rights in the short term, but states must progressively make efforts to assist all citizens to realize these rights over time

UNCRC

- Principles
 - Non discrimination
 - Best interest of the child
 - Survival and development
 - Respect for the view of the child
- Also acknowledges that children with disability require additional or different forms of support to enjoy their rights
Brester, 2004
- General tendency in developing countries to present overly prescriptive agendas and to assume that interconnected issues need to be simultaneously be addressed
Alston, 2005

BECAUSE
EVERY CHILD
IN THE WORLD
HAS ONE THING
IN COMMON.
THEIR RIGHTS.

Children with disability

- Children with disabilities 's voices are often not heard – even in developed countries such as the UK which actively advocates for the rights of people with disability [Mitchell, 2010](#), [Wright, 2008](#)
- Research methodologies are often not appropriate for children with disability [Sullivan, 2009](#)
- Significant research time required when conducting research with children with disability [Andrews 2005](#)
- Researcher's have to not only recognize that children with disability have a voice, but have to work actively towards eliciting their views, [Lewis & Porter, 2004](#)
- Current study used Talking Mats Procedure to allow children to voice their own opinions [Murphy & Cameron, 2008](#)



Why include children in research ?

- Contributes to their social competence and responsibility
United Nations Children's Fund, 2010
- Children felt it made them visible (as opposed to "*children should be seen and not be heard*")
- Enabled them to be included in the design of legislation, policy and intervention programs affecting themselves *Viviers, 2010*
- Participation regarding their rights is thus a sound social economic investment in their future *Landsdown, 2005*



Aim of the project

- To investigate the rights of children (between 8 and 14 years of age) with intellectual disabilities in South Africa.
- Due to progressive realization and economic constraints, positive human rights may be unmet for children (particularly in high risk environment)
- This was determined by asking children with intellectual disabilities and their primary caregivers about their home environment



Participants

- 220 8 -14 year old children with mild – moderate intellectual disabilities
- 220 primary caregivers (mostly parents) of these children
- All children were enrolled in 11 special schools for children with intellectual impairments across 4 provinces
- Two urban and 2 rural contexts
- Language of instruction at special schools represented 4 language groups:

isiZulu (n=64)

Afrikaans (n=55)

English (n=51)

Xitsonga (50)



Instrument

Section 1: Biographical information



Section 2: The Ten Question Questionnaire [Durkin, 2001](#)

TQQ is a standardized screening tool that was developed as a rapid, low-cost screening method to assist in the identification of children aged 2-9 years with serious disabilities in diverse cultures where professional resources were extremely scarce [Durkin, Hasan & Hasan, 1995](#); [Alcock, Carter, Meehan, Mturi, Mung'ala-Odera & Newton, 2004](#).

Section 3: Questions related to human rights of children with intellectual disability

Instrument : Examples from some of the items

Nr	Question	Child / parent	ICF-CY code	UNCRC article	Maslow
26	Does your child have clean water to drink at home? <i>Do you have clean water to drink at home?</i>	P C	e1100	Article 6 Article 24 Article 27	Physiological
27	Does your child have food to eat at home? <i>Do you have food to eat at home?</i>	P C	e1100 e310 e315	Article 6 Article 24 Article 27	Physiological
28	Does your child have his/her own bed to sleep in at home? <i>Do you have your own bed to sleep in at home?</i>	P C	e1150	Article 25	Physiological
29	Does your child have something to play at home? <i>Do you have things to play with at home?</i>	P C	e1152	Article 31	Love / Belonging Esteem



Study 1

Lygnegård, Donohue, Bornman, Granlund & Huus, 2014

Journal of Policy Practice, 12:296–315, 2013
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ISSN: 1558-8742 print/1558-8750 online
DOI: 10.1080/15588742.2013.827141



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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Study 1

Lygnegård, Donohue, Bornman, Granlund & Huus, 2014

- **Aim** : To conduct a systematic review of the needs of children with disabilities living in poverty settings in LAMI countries.
- **Results:** Needs at the first level of Maslow's Hierarchy of Needs, are more frequently researched in LAMI countries, whereas higher-order needs are not.
- **Conclusion:**
 - Higher order needs should be further explored.
 - Children's own voices should be taken into consideration when designing policies and services aiming at increased service user empowerment, in line with CRC.

Study 2

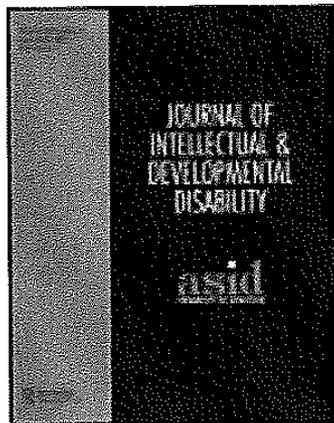
Donohue, Bornman & Granlund, 2014

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Publisher: Routledge

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Journal of Intellectual and Developmental Disability

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/cjid20>

Examining the rights of children with intellectual disability in South Africa: Children's perspectives

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Published online: 18 Nov 2013.

To cite this article: Dana K. Donohue, Juan Bornman & Mats Granlund (2014) Examining the rights of children with intellectual disability in South Africa: Children's perspectives, *Journal of Intellectual and Developmental Disability*, 39:1, 55-64, DOI: [10.3109/13668250.2013.857769](https://doi.org/10.3109/13668250.2013.857769)

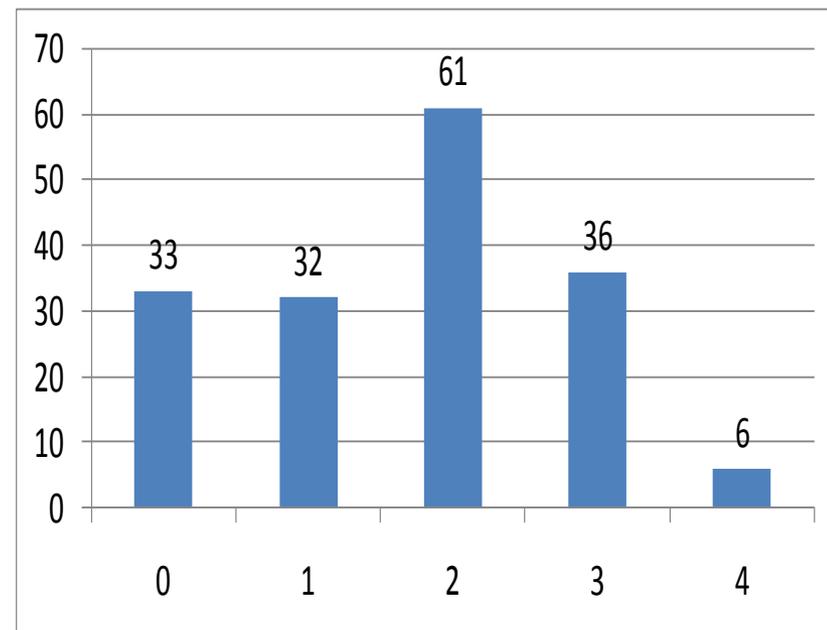
To link to this article: <http://dx.doi.org/10.3109/13668250.2013.857769>

Study 2

Donohue, Bornman & Granlund, 2014

Aim : To determine how socio-economic and other risk factors were associated with the positive human rights of children with intellectual disabilities from the children's perspective

Construct	Low risk	High risk
Household income	> R60,000	< R60,000
Education	Grade 12 or more	Grade 10 or less
Nr of people in home	6 or less	7 or more
Single parent	Yes	No



Study 2

Donohue, Bornman & Granlund, 2014

- **Results:** Participants reported general high degrees of access to basic resources.
- Logistic regression suggested socio-economic risk factors (education, income, household size relationship status) were negatively related to children's report of access to food, and their own bed to sleep in, and
- Positively related to having somebody available to explain confusing things to them.
- **Conclusion:** Positive human rights (right to be provided with something, e.g. food and housing) of children living in high-risk environments should be monitored to ensure that all children have their rights met.

Household size is associated with unintelligible speech in children who have intellectual disabilities: A South African study

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Abstract

Objective: The purpose of this study was to examine whether four socioeconomic factors, namely caregiver age, caregiver education, family income and/or household size were related to the presence of motor delays or unintelligible speech in South African children with intellectual disabilities. **Methods:** Caregivers of children with intellectual disabilities completed a biographical questionnaire regarding their home environments. Other items on the questionnaire queried whether their children experienced co-occurring developmental impairments of motor delays or unintelligible speech. **Results:** A total of 145 caregivers were included in the analyses. Two logistic regressions were run with the set of four socioeconomic factors as predictors, and motor delays and intelligible speech as the outcome variables. Household size was a statistically significant predictor of whether children evidenced intelligible speech. **Conclusion:** Children living in dwellings with more people were less likely to have intelligible speech. The processes through which large household size might influence children's language are discussed.

Introduction

According to the American Association of Intellectual and Developmental Disabilities [1], intellectual disability occurs when individuals experience significant limitations in adaptive behaviour and intellectual functioning, both beginning before 18 years of age. The majority of children with intellectual disabilities evidence less pronounced, or mild to moderate intellectual disabilities, and often there is no clear origin of their disabilities [1]. Statistics SA [2] reported in 2001 that about 5% of the South African population had a disability, and of those individuals, 12.4% had an intellectual disability. Children with intellectual disabilities are often exposed to co-occurring conditions. According to Rosenberg and Abbeduto [3], delays in language development are

Keywords

Household size, intellectual disability, motor delays, risk factors, South Africa, unintelligible speech

History

Received 28 January 2014
Accepted 28 January 2014
Published online 26 February 2014

These co-occurring conditions may aggravate or be aggravated by living in a poverty setting.

Zigler and Hodapp [8] suggested that while mothers from varying socioeconomic backgrounds have children with congenital disabilities at similar rates, children with less pronounced intellectual disabilities disproportionately reside in families who live in poverty. While tracking a sample of low birth weight infants from different socioeconomic strata who all evidenced typical intelligence at birth, Escalona [9] found, for example, that at 28 months of age, children living in impoverished homes experienced significant cognitive declines when compared with their more economically advantaged same-age peers. This intellectual gap persisted when the children were again assessed at 40 months of age.



Study 3

Donohue, Bornman & Granlund, 2014

- **Aim** : To examine if four socioeconomic factors, namely caregiver age, caregiver education, family income, and/or household size were related to the presence of motor delays or unintelligible speech in South African children with intellectual disabilities.
- **Results**: Logistic regressions showed that household size was a statistically significant predictor of whether children evidenced intelligible speech.
- **Conclusion**: Children living in households with more people were less likely to have intelligible speech
 - impoverished living conditions are stressful and hinder optimal parenting
 - overcrowding may expose children to more environmental toxins

Study 4

Huus, Granlund, Bornman, Lygnegård, submitted

- **Aim** : To compare children with intellectual disability's own ratings (as self-raters) to those of their primary caregivers (as proxy raters) regarding children's human rights. To establish whether there is an inter-rater agreement between the self-raters and proxy raters concerning Maslow's hierarchy of needs.
- **Results**: Questions regarding basic needs (clean water & food) were answered similarly by self-raters and proxy raters. Questions about friends to play with at home and toys yielded biggest differences. Also, socioeconomic variables seemed to affect whether self-raters and proxy raters would answer similarly.
- **Conclusion**:
 - Consider opinions of both the children and their primary caregivers.
 - Agreement is affected by socio-economic circumstances.
 - Children need to be included when more complex needs are surveyed.

Study 5

Huus, Bornman, Lygnegård & Dada, in progress

- **Aim** : To compare the perceptions of parents living in rural and urban area's of the rights of their children with disabilities, in terms of protection, provision and participation rights. Open ended question was asked.
- **Results:**
 - **94,8%** of Urban parents said “YES” vs **73,6%** Rural parents
 - Urban parents mentioned a mean of 4 rights, and rural parents mentioned 3 rights
 - Of the 54 articles in the UNCRC, parents mentioned 22 rights and 6 showed significant differences.
 - The Right to Education was named most frequently : 129 times in total, 55 times by urban parents, and 74 times by rural parents. Bear in mind, all of these children were already in school – what is the implication of that?
 - All other rights mentioned more frequently by urban parents.

Study 5

Huus, Bornman, Lygnegård & Dada, in progress

Children's rights expressed by parents	Article UNCRC	Provision, protection, participation	Urban	Rural	Total	Pearson	P
Right to protection from the state when maltreated	21	protection	45	25	70	11.007	0.001
No discrimination based on race, sex, disability etc.	2	protection	30	14	44	9.035	0.003
Right to maximize child's potential for development	6	provision	26	16	42	4.057	0.044
Education to self-actualize child	29	provision	22	6	28	12.066	0.001
Right to privacy	16	provision	6	0	6	6.698	0.010
Right to an identity, including nationality and family relations	8	provision	4	0	4	4.424	0.035

Study 5

Huus, Bornman, Lygnegård & Dada, in progress

- **Conclusion:**
 - Provision rights are the prerequisite to participation rights
 - Parents in urban areas, are more aware of which possibilities exist and are better equipped to provide their children with opportunities to fulfil their rights.
- **Next steps...**
- To classify these rights according to Maslow's hierarchy. Initial results seem to indicate that the parents focused more on higher order needs (love and belonging) than on lower order needs (food, water, etc)

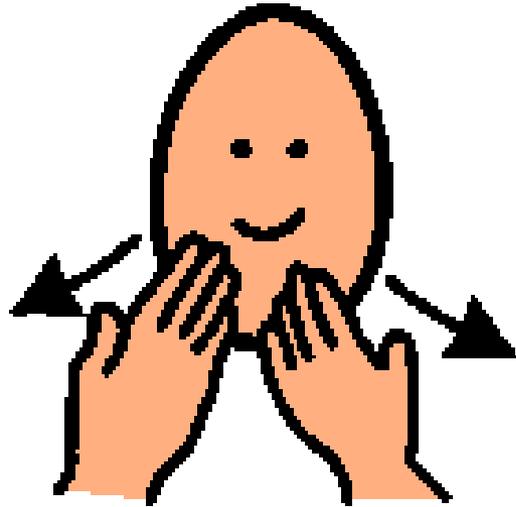
Concluding thoughts ...

- **Nothing about us without us!** Unifying slogan of disability rights government in SA
- Echoes the sentiments of Post apartheid democracy which focuses on “participatory democracy”
- “Know your constitution” campaigns
- Parents face different participation barriers:
- **Elizabeth: Will her 6-year old son be accepted into school?**
- **Maria: Experiences stigma – painfully told her that community members told her that her son looks like a “cockroach”, with a head that looked like “a loaf of brown bread”**

Concluding thoughts ...

- Participation of children with intellectual disabilities is increasing, but still lacking behind typically developing peers [Franklin & Sloper, 2009](#)
- Ensuring participation for these children by addressing provision and protection rights should not only be driven by compelling statistics, but also by listening to the real life difficulties experienced by these individuals and their families as they try to access their human rights.
- Trying to understand participation and the rights of these children is a “living project” – the last words have not been spoken. We need to keep considering all aspects so that we do not obstruct our progress in the field.

Thank you! Dankie! Siyabonga!



Students & staff collaborating on the project:

Priscilla Kershaw Alta Erasmus Susan Pelembe Hlengiwe Ntuli
Alecia Samuels Sneha Dosieah Dana Donohue Ensa Johnson
Kitty Uys Enid Moolman Karin van Niekerk Simon Sikhosana
Conny Simelane Erina Acres Kerstin Tonsing Shakila Dada

