CHILDHOOD DISABILITY SURVEYS: AN INQUIRY INTO PARENT-REPORTED MEASUREMENT INSTRUMENTS FOR THE XHARIEP

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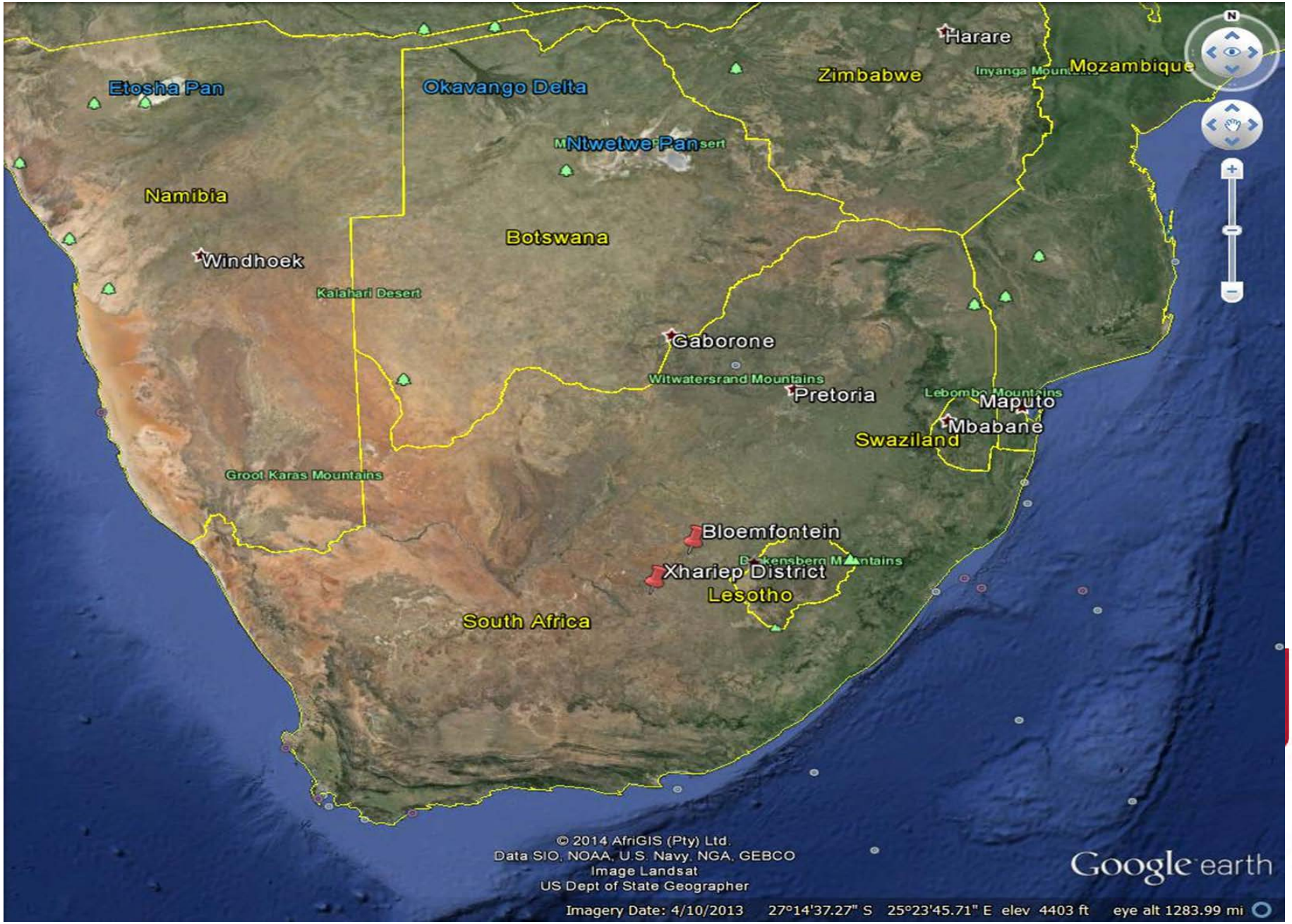
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CONTEXT OF THE STUDY

- South Africa: **52,98 million**
- **29,2%** younger than 15 years
- Infant mortality **41,7**/1 000 live births
- Free State Province (1:9 provinces)
- **Free State** population: 2 753 200 5 **5,2 %** of total SA population
- **Xhariep district**

(StatsSA, 2013)

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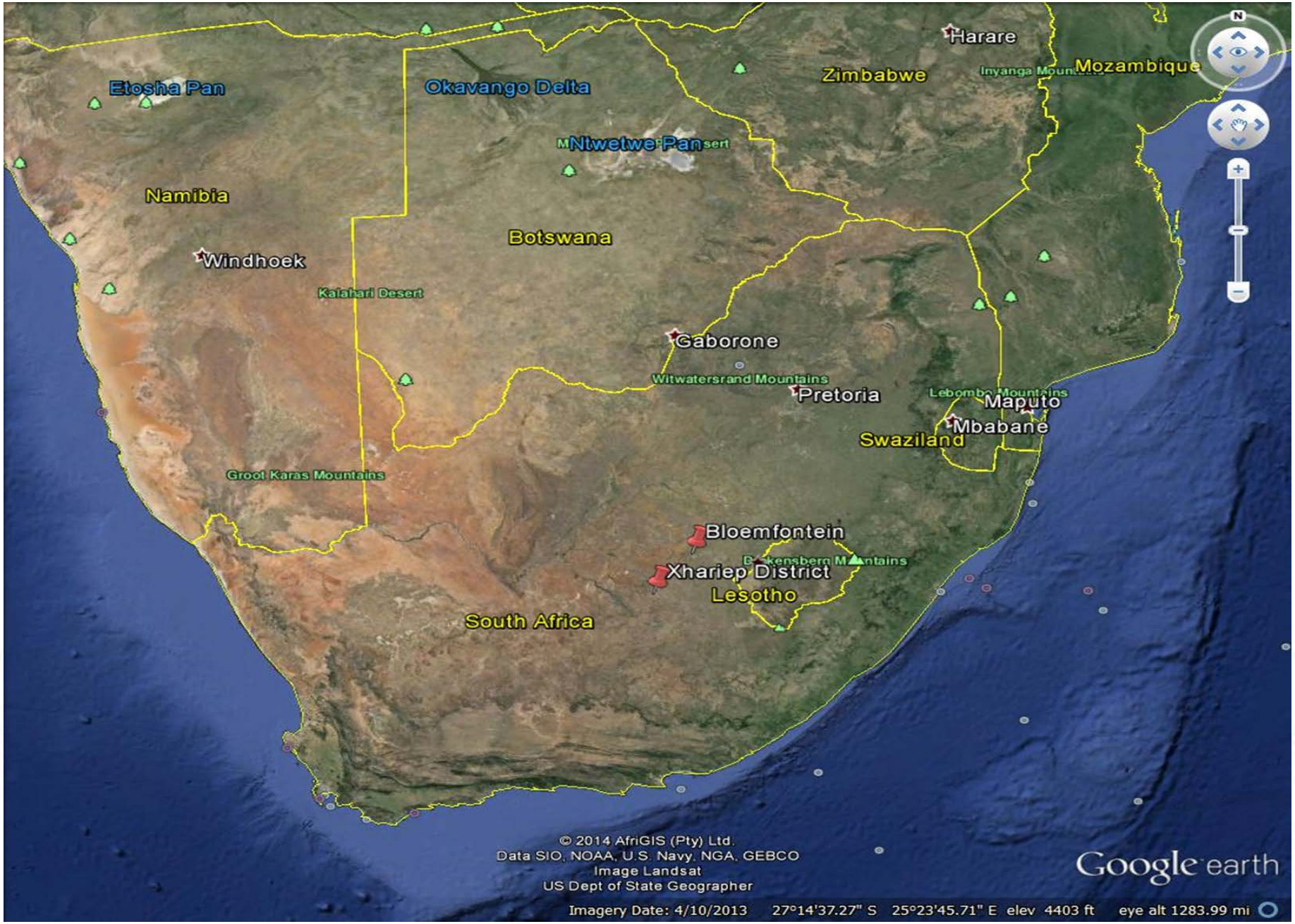
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ESTIMATED % OF PEOPLE WITH DISABILITIES

Source	Year	%	Question to determine disability
Global			
World Report on Disability: 1. World Health Survey 2. WHO Global Burden of Disease study	2002-2004	15.6 %	
National			
Census	2001	5 %	Included children under 5 years
Global Burden of Disease study	2004	12.2 %	
Community survey (Stats SA)	2007	5.7 %	
General Household Survey	2009	5.6%	Excluded children under 5. Methodology based on ICF and adapted questions used from United Nations Washington Group on Disability Statistics.
Census	2011	7.5%	

ESTIMATED % OF CHILDREN WITH DISABILITIES

Source	Year	%	Question to determine disability
Global			
State of the World's Children 2013: Children with Disabilities (UNICEF 2013)	2013	0.5 %	
National (0-4 years)			
Census	2001	1.6 %	Does the person have any ***serious disability*** that prevents full participation in life activities?
Community survey	2007	0.9 %	Does the person have any ***kind of disability***?
General Household Survey	2008	0.6 %	Is the person ***limited*** in ***daily activities*** because of a ***condition*** longer than 6 months?
Census	2011		Children under 5 not included
2021 Census & General Household Survey	**?**	**?**	**United Nations** & **Department Children & people with Disabilities SA is in process since** 2014 to develop a **Module to Measure Disabilities of children 0-4 years.**

EPIDEMIOLOGY

- Discrepancies in childhood disability data *(Bjorn Gelders UNICEF SA, 2011)*
  - Measures/Questions
  - StatsSA excluded children under 5 in 2011 census
- Relatively low prevalence rate → High mortality rate *(World Health Organisation, 2013)*
- Inadequate health services *(Durkin et al., 1994)*
- Disability rates increase with age *(Couper, 2002; Milaat, Ghabrah, Al-Bar, Abalkhail, & Kordy, 2001; WHO, 2011)*

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"THE GAP"

There is no comprehensive

National or international

child disability surveillance instrument,

compatible with the ICF,

methodologically sound, to provide

internationally comparable data

on child disability available in SA.

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BACKGROUND

- Faculty of Health Sciences, University of the Free State
- Proposed rural birth-cohort study (FIT)
- Two of focus areas: Developmental trajectories & Prevalence of disabilities
- Pilot study nested in larger protocol
- Xhariep district

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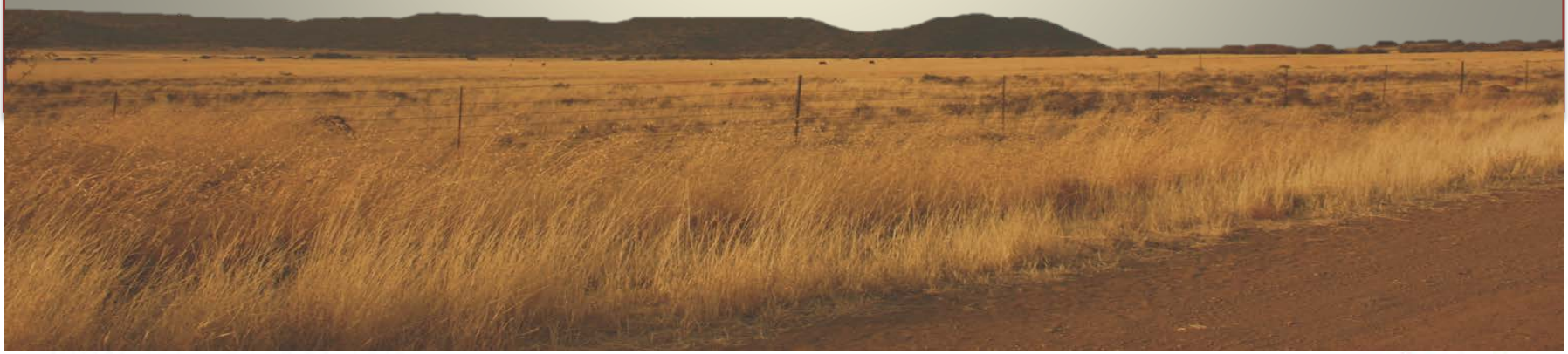
ALIGNING THIS RESEARCH

- **Internationally:** Collaborating and aligning with WGDS work
- **Nationally:** Department of Children and People with Disabilities and Stats SA *(UNDP &Stats SA, 2013)*
- **University:** Rural birth-cohort project Faculty of Health Science *(Walsh, 2012)*



AIM

Investigate the **sensitivity and specificity**
of **translated versions** of the
Ages-&-Stages, Third Edition (ASQ-III) &
***Washington Group on Disability Statistics (WGDS)* 2013**
***Module* on Child Functioning and Disability,**
as **parent-reported** measurement instruments
to identify early **childhood disabilities** in children,
24-48 months, in the **Xhariep** District.

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SENSITIVITY & SPECIFICITY

- **Sensitivity**: the proportion of true positives that are correctly identified by the test

- **Specificity**: the proportion of true negatives that are correctly identified by the test

(Grove, Burns & Gray, 2013; Polit & Beck, 2010)

PARENT-REPORTED MEASURES

	ASQ-III	WGDS
Standardised	1 to 66 months USA	48 months – 17 years 2014 latest version
Domains	1. Communication 2. Gross motor 3. Fine motor 4. Problem solving 5. Personal-social	1. Seeing 2. Hearing 3. Walking 4. Communication 5. Learning 6. Playing 7. Behaviour

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PARENT-REPORTED MEASURES

	ASQ-III	WGDS
Possible responses	Yes (10) Sometimes (5) Not yet (0)	No difficultly (0) Some difficulty (1) A lot of difficulty (2) Cannot do at all (3)
Sensitivity & Specificity	Sensitivity 75% Specificity 86%	2014 latest edition

(Gollenberg, Lynch, Jackson, McGuinness, & Msall, 2009)

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METHOD

- Forward-backward translation
- To Afrikaans & SeSotho
  - Available for future studies
- Adjust → cultural relevance

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METHOD

- **Study design:** Quantitative, observational descriptive
- **Study setting**:
  - **Xhariep district** geographically largest of 5 Free State areas
  - **Kopanong district** covers around 15190 square kilometres
  - One district hospital and one clinic
  - Rural population
  - Multilingual (SeSotho, Afrikaans, English)
  - Six towns in Kopanong district, Xhariep

METHOD

- **Study sample**:
  - 50 caregivers of children 24-48 months
  - **South African Social Security Agency** (SASSA) database
  - Sampling: non probability convenience sampling
  - SASSA grant beneficiaries
    - Child support (CSG)
    - Foster care grant (FCG)

    → Typical development
    - **Care dependency** grant (CDG) → Disability
    - Gold standard

DATA COLLECTION PROCEDURE

- SASSA employee/community health worker
- At multi-purpose centres
- Standard set-up & procedure → reliability
- Informed consent
- Structured interviews: parent-reported questionnaires
- Detection of disability → health care services

DATA ANALYSIS

- UFS Department of Biostatistics
- **Descriptive statistics**:
  - Frequencies, percentages, standard deviations, medians & percentiles
- **Sensitivity, specificity**, predictive values & likelihood ratios

METHOD: ETHICAL CONSIDERATIONS

- Ethical clearance
- Permission from stakeholders
  - Xhariep District Municipality & SASSA
- Permission from publishers
  - ASQ-III (purchased) & WGDS
- Informed consent & referral

RESULTS

- 50 caregivers: 5 care dependency grants
- Relationship: 36 mothers, 13 grandparents, 1 foster parent
- Afrikaans (31), English (18) & Sesotho (1)
- Highest educational level Grade 12 (National Certificate)

  Only obtained by 34%
- Ease of completion: *(Rydz, et al., 2006).*
  - WGDS easier than ASQ
  - Difficulty of understanding
  - Knowledge of child versus concepts

RESULTS: SENSITIVITY

	Parameters		95 % Confidence Intervals	
	ASQ-III	***WGDS***	***ASQ-III***	***WGDS***
Sensitivity	60.0%	60.0%	[15% ; 95%]	[15% ; 95%]
Specificity	95.6%	84.4%	[85% ; 99%]	[71% ; 94 %]
+ Predictive value	60.0%	30.0%	[15% ; 95%]	[7.0% ; 65%]
– Predictive value	95.6%	95.0%	[85% ; 99%]	[83% ; 99%]
+ Likelihood ratio	13.5	3.857	[2.92 ; 62.48]	[1.44 ; 10.36]
– Likelihood ratio	0.419	0.474	[0.14 ; 1.23]	[0.16 ; 1.40]

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RESULTS: SPECIFICITY

	Parameters		95 % Confidence Intervals	
	ASQ-III	***WGDS***	***ASQ-III***	***WGDS***
Sensitivity	60.0%	60.0%	[15% ; 95%]	[15% ; 95%]
Specificity	95.6%	84.4%	[85% ; 99%]	[71% ; 94 %]
+ Predictive value	60.0%	30.0%	[15% ; 95%]	[7.0% ; 65%]
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+ Likelihood ratio	13.5	3.857	[2.92 ; 62.48]	[1.44 ; 10.36]
– Likelihood ratio	0.419	0.474	[0.14 ; 1.23]	[0.16 ; 1.40]

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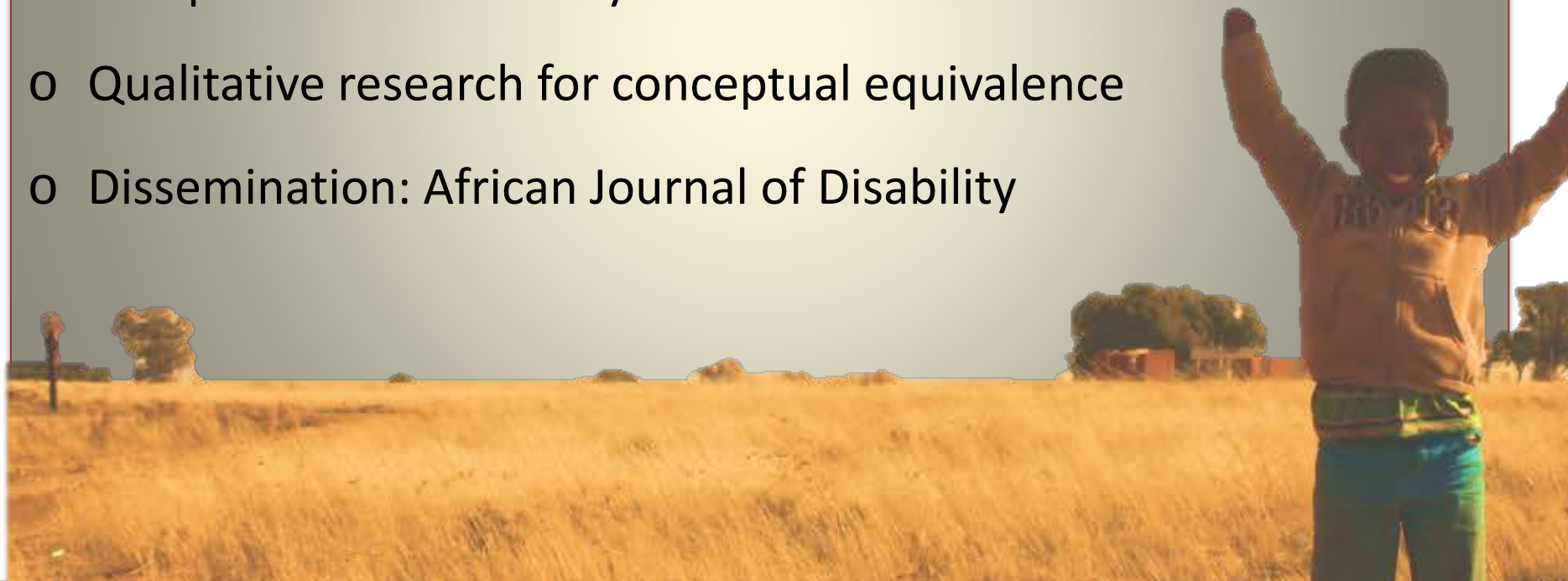
LIMITATIONS

- Small sample size
- Clinical assessments / Clinic records

RECOMMENDATIONS

- Further researchers on larger samples
- Collaboration with StatsSA's working group: 2021 Census question for children under 5
- Comparison of this study's
- Qualitative research for conceptual equivalence
- Dissemination: African Journal of Disability



CONCLUSION

- Both measures are specific; however, not as sensitive
- WGDS was easily understood
- ASQ-lll, clinical measure potential for identifying disabilities
- WGDS potential usefulness population-based & smaller scale
- Advantages of WGDS
- WGDS support to development of Stats SA questions

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- UFS Department of Occupational Therapy
- Regional & District Offices of SASSA
- District Occupational Therapy Services

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"Each one of you is your own person, endowed with rights, worthy of respect and dignity. Each one of you deserves to have the best possible start in life, to complete a basic education of the highest quality, to be allowed to develop your full potential and provided the opportunities for meaningful participation in your Communities."

Nelson Mandela (UNICEF, 2000)

REFERENCES

- Bjorn Gelders UNICEF SA. (2011). Childhood Disability in South Africa: Results from an Analysis of the Census 2001, Community Survey 2007 and General Household Survey 2008-2009.
- Couper, J. (2002). Prevalence of Childhood Disability in Rural KwaZulu-Natal. *South African Medical Journal*, *92*, 549–552.
- Durkin, M. (2002). The epidemiology of developmental disabilities in low-income countries. *Mental Retardation and Developmental Disabilities Research Reviews*, *8*(3), 206–11.
- Gollenberg, A.L., Lynch, C.D., Jackson, L.W., McGuinness, B.M., & Msall, M.E. (2009). Concurrent validity of the parent-completed Ages-&-Stages Questionnaires, 2nd Edition with the Bayley Scales of Infant Development II in a low-risk sample, (p. 485-490). *Child: Care, Health and Development, 36*(4).
- Grove, S., Burns, N., & Gray, J. R. (2013). *The Practice of Nursing Research: Seventh Edition* (p. 422). St. Louis: Elsvier Saunders.
- Milaat, W., Ghabrah, T. M., Al-Bar, H. M., Abalkhail, B., & Kordy, M. N. (2001). Population-based survey of childhood disability in eastern Jeddah using the ten questions tool. *Disability and Rehabilitation*, *23*(5), 199–203.

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REFERENCES

- Polit, D.F., & Beck, C.T. (2010)., *Essentials of Nursing Research: Appraising Evidence for Nursing Practice - Seventh Edition* (p. 381).
- Rydz, D., Srour, M., Oskoui, M., Marget, N., Shiller, M., Birnbaum, R., et al. (2006). Screening for Developmental Delay in the Setting of Community Pediatric Clinic: A Prospective Assessment of Parent-Report Questionnaires, (p. e1178-e1186). Official Journal of the American Academy of Pediatrics, 118(4).
- Statistics South Africa. (2013). Statistical release: Mid-year population estimates, (July 2012).
- South African Social Security Agency (SASSA)
- WHO. (2011). *WORLD REPORT ON DISABILITY*. Geneva.
- World Health Organisation. (2013). World Health Statistics 2013. Geneva: WHO.

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