

Towards the quantification of intellectual disability in children and adolescents in Africa: an exploration of the psychometric properties of the Wessex Behaviour Schedule (WBS) in Khayelitsha, South Africa

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ABSTRACT

Background: Intellectual Disability (ID) is important and has a major impact on life, quality of life, mental illness, economic and educational well-being. Little research has taken place in Africa about ID. One of the key challenges is to identify appropriate, useful, and free screening tools that might identify those at risk of ID both for clinical purposes and for prevalence studies. One tool that has been used to investigate the broad category of 'disability' (which includes ID) is the Ten Questions Questionnaire (TQQ). The TQQ has given some rates of 'disability' in low- and middle-income countries (LMICS) in the order of 10-25%. However, no further dissection of ID within the broader category of 'disability' has been performed given that the TQQ was not developed with ID in mind. The Wessex Behavioural Schedule (WBS) is a UK screening tool for functional ability for adults with ID, and therefore seemed an appropriate candidate instrument to evaluate for potential use in Africa. However no psychometric data for the tool were available and no clinical cut-off scores for ID had ever been developed. A broader project using the WBS in Khayelitsha, a township area in Cape Town, South Africa, generated a prevalence rate of 19% 'disability'. The purpose of this study was to explore the psychometric properties of the WBS to determine its suitability for use in children and adolescents in a South African setting, and to generate clinical cut-offs to define ID.

Methods: The study consisted of a secondary analysis of the data from the broader Khayelitsha prevalence study, which was a cluster randomized door-to-door household survey in Khayelitsha using the WBS. Firstly, data were used to evaluate the internal consistency and to perform factor analysis of the WBS. Secondly, the Minimal Difference Perceived 75% of time (MDP75) approach was used on a subset of 100 randomly selected participants to generate an intellectual disability cut-off score for the WBS.

Results: Data were available on 452 children and adolescents aged 5-18 years. The mean age was 10.3 (SD 3.9), 54% were female, over 90% were in school, and 53% had a mother as primary carer. The WBS had good internal consistency ($\alpha = 0.80$) and all items appeared to be worthy of retention. Exploratory factor analysis suggested the WBS to be a multidimensional scale composed of four subscales: conceptual abilities, practical skills, sensory abilities and continence. Even though four expert raters were used for the MDP75 calculation, inter-rater reliability was low-58% (Fleiss kappa = 0.08). It was therefore not deemed appropriate to proceed to further analysis to determine the MDP75 and cut-off values for the WBS. Possible reasons for low inter-rater reliability suggested by the raters included age-based expectations, inclusion of physical disabilities, limited information to make a diagnosis of ID contained in the WBS, and the need to take environmental factors into consideration.

Conclusion: The good internal consistency and factor analysis structure of the WBS was encouraging, but the low inter-rater reliability brought into question the usefulness of the WBS in a child and adolescent age group. Whilst the WBS may remain useful in an adult age range, we recommend that a more developmentally-sensitive measure be sought or developed as a screening tool for ID.

Keywords: Wessex Behavioural Schedule, children and adolescents, intellectual disability, Khayelitsha

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ABBREVIATIONS

ID- Intellectual disability

WHO- World Health Organization

APA- American Psychiatric Association

WBS– Wessex Behavioural Schedule

DSM-IV-TR-Diagnostic and Statistical Manual of Mental Disorders- Fourth Edition (Text Revision)

DSM-5- Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition

AAIDD- American Association on Intellectual and Developmental Disabilities

LMIC-Low- and Middle-Income Countries

OPERATIONAL DEFINITION OF TERMS

Child: According to United Nations' Convention on the rights of the Child, a child means every human being below the age of eighteen years. Unless under the law applicable to the child, where age of majority is attained earlier (United Nations, 1989, U.N. General assembly, 1989)

Adolescent: World Health Organization defines an adolescent as that person between 10 and 19 years of age (WHO. et al., 2005)

Disability and impairment: Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (WHO, 2007).

Intellectual Disability: According to the DSM-5, Intellectual Disability is characterized by significant limitations in general mental abilities and adaptive functioning that emerge during the course of children's development. Limitations must be evident in comparison to other people of the same age, gender, and social-cultural background (APA, 2013); see page 2 for different levels of ID.

Global developmental delay: Global Developmental Delay (GDD) is a neurodevelopmental disability that is only diagnosed in children less than 5 years of age (APA, 2013). GDD is diagnosed when the infant or child fails to meet developmental milestones in several areas. GDD is usually diagnosed in infants and toddlers who show significant delays in two or more of the following developmental domains: (a) fine/gross motor skills, (b) speech/language, (c) social/personal skills, and (d) daily living. *Significant delays* are defined by scores two or more standard deviations below the mean. Typically, children with GDD show delays across most or all domains of functioning (Shevell, 2010, Bilder et al., 2013).

1. CHAPTER ONE: INTRODUCTION

Intellectual disability (ID) is a neurodevelopmental disorder that has a major impact on adaptive behaviour and daily living skills of those affected, has a significant burden of care and very significant health economic implications. As a result of meeting the needs of their child with ID, many families do without earnings as they spend less time in paid jobs. In one study, Parish and others compared parents with and without children with developmental disability and reported that mothers of children with disabilities were less likely to have jobs lasting 5 years or more and had inferior earnings at age 36 years (Parish et al., 2004). An enormous array of needs is linked to caring for children with developmental disabilities, including respite care, specialized therapies, protracted diagnostic tests, medication, home modifications, specialist educational services and adaptive equipment (Parish et al., 2004). Furthermore, research done in high-income countries has consistently shown an association of poverty and ID (Emerson, 2007).

Intellectual Disability can range from mild to profound, and is associated with various developmental and behavioural manifestations and a growing number of underlying recognized etiologies (Maulik PK, 2010). The World Health Organization defines ID as a condition that begins in the developmental period, and states that the individual has “*a significantly reduced ability to understand new or complex information and to learn and apply new skills resulting in a reduced ability to cope independently with lasting effect on development*” (WHO,1992). In DSM-5, ID is classified under neurodevelopmental disorders where the term *intellectual disability* replaced the term ‘mental retardation’ previously used in DSM-IV (APA, 2013). The term ‘intellectual developmental disorders’ has been proposed for ICD-11 (APA, 2013,Carulla et al, 2011). The new DSM-5 criteria emphasize the importance of determining adaptive functioning alongside the measurement of IQ-Intellectual Quotient (APA, 2013). In DSM-IV, severity of ID was classified based on the performance of an individual on IQ-type tests, and was described as mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 21-34) and profound (IQ<20). In DSM-5,

the severity specifiers of ID have remained as in DSM-IV (mild, moderate, severe, profound), but IQ as main predictor of severity has been removed. This subtle but definite conceptual shift away from psychometric definition to incorporate a functional definition of disability reinforces the importance to reinvestigate potential measurement tools of functional ability as predictors of intellectual disability. The main goal of WHO Mental Health Gap Action Programme (http://www.who.int/mental_health/mhgap/en/) is to improve opportunities of access to care by expanding services for mental, neurological and substance use disorders for Low and Middle Income Countries (LMIC). Further, maternal alcohol use disorder is the leading known risk factor for ID with no identified genetic origin (O'Leary et al., 2013). The ID occurring as part of the foetal Alcohol Syndrome Disorder (FASD) has a prevalence rate in South Africa several times higher than elsewhere in the world (Olivier et al., 2016). The present study was conducted to examine the psychometric properties of a functional screening instrument for ID, the Wessex Behaviour Scales (WBS), in children and adolescents aged 5-18 years. We aimed to evaluate internal consistency and factor structure of the WBS, and to generate clinical cut-off values to define intellectual disability using the WBS.

1.1 The prevalence of ID and associated socio-demographic factors

Prevalence data are limited, particularly in children and adolescents. Harris in 2006 reported the prevalence of ID to range between 1% and 3% worldwide (Harris, 2006) and the rates reported in children are between 3-14/1000. Maulik and others (2010) in their review reported whole population of children, adolescents and adults ID rates of 1% for High Income Countries (HIC) and 2% LMICs. Another of their key findings was that studies on children and adolescents showed elevated prevalence rates. Prevalence of ID is reported to be higher in males in children and adolescents, as well as adult populations. In children and adolescents the female to male ratio ranges between 0.4:1 and 1:1 (Harris, 2006). Other factors that have been described as

modifiers of prevalence or possible contributing factors to differing prevalence rates include the severity of ID, age, study population, and socio-economic status (Maulik et al., 2011a).

Two previous literature reviews on ID by Njenga (2009) and Adnams (2010) both commented on the scarcity of prevalence studies in Sub-Saharan Africa (Njenga, 2009, Adnams, 2010). The few studies done in Sub-Saharan Africa reported prevalence rates up to twice those reported in high-income countries. Arguably the most comprehensive study to date in South Africa was performed by Kromberg et al in the Bushbuckridge district of South Africa. Their study of the prevalence of ID in rural black children reported a prevalence of 3.3% (Kromberg et al., 1997b). In the same district Christianson and colleagues reported prevalence of 0.64 per 1000 of severe ID and 29.1 per 1000 of mild ID (Christianson et al., 2002). Kleintjes et al in 2006 reported a prevalence of ID of 3% in the Western Cape (Kleintjes et al., 2006).

The few studies measuring prevalence of ID in children and adolescents in Africa were hampered by methodological challenges. First, the need for large-scale epidemiological samples makes studies potentially very expensive. Secondly, to carry out an epidemiological survey, it is necessary to have consistent case definition of ID. As noted above, the definition of ID has changed over time (Smiley, 2005). In addition, a major challenge in an African setting is the availability of standardized measurement tools that are culturally and contextually appropriate. In the South African setting, performance on IQ tests has, for instance, been shown to be strongly predicted by educational quality of participants (Maswikiti, 2010). Furthermore, an IQ assessment should ideally be done in the primary language of a participant by a professional who can speak the same primary language. This is not possible in a South African setting for all sectors of the population, given scarce availability of tools and trained users and the fact that at least eleven primary languages are in common use. When considering tools to measure adaptive behaviour, the most widely used tool in South Africa is the Vineland Adaptive Behavior Scales (VABS), currently in its third edition (VABS-3). However, the VABS is costly, requires skilled administrators, and, to date, no African or South African studies have been published to

evaluate the usefulness of the VABS in a local setting. We are aware of a study currently underway (personal communication: Gill Douglas), but results are not yet published.

Just as in high-income countries, in LMIC, developmental disorders have been associated with high disability burden, human rights violation and high financial costs (Fischer et al., 2014). In this regard, the WHO included these conditions to be tackled by the mhGAP Intervention Guide (Patel and Thornicroft, 2009). The mhGAP is a clinical guideline for assessment and management of leading mental, neurological and substance-abuse conditions by non-expert primary care workers. The guide presents a step by step direction to diagnosis and management of developmental disorders at primary healthcare level (WHO, 2015). Still, the absence of tools for assessment and monitoring of child development including intellectual ability, suitable for use by non-experts in resource limited settings impedes the opportunity of establishing mhGAP in child healthcare services (Fischer et al., 2014).

Indeed, this point was highlighted in the report by Tomlinson et al. of global research priorities for ID and ASD in children and adolescents in LMIC. There was high consensus of an international expert panel of the need for health services to address effective early identification, screening and early intervention in this group (Tomlinson et al., 2014).

Case detection of children and adolescents with ID who possibly are in need of early intervention necessitates the application of a tool for assessment and diagnosis that is valid and developmentally sensitive. While standardized tools from HICs provide assessment tests that have been well-validated in their settings, the transfer of these tests to LMICs contexts is associated with major limitations of interpretations of the scores and practicability of use in settings with limited resources (Greenfield, 1997, Abubakar et al., 2008). Even in HIC there are not really any good screening tools for ID. When it comes to early detection of developmental disability, the main challenge is possessing tools that are sensitive to contextual diversity such as cultural concepts of disability. Such a tool may be employed transversely to diverse cultures (Fischer et al., 2014). A particular concern of comparability of assessment procedures arise

when comparing and contrasting test results across different populations that are diverse in language and other facets of culture. Cross-cultural agreement is particularly challenging especially when assessments rely on spoken accounts of persons sampled from the population (Fischer et al., 2014). In such occurrences, it is crucial to illustrate that population characteristics, for example, educational level, cultural values and favored language do not influence the quality of the assessment (Fischer et al., 2014, Durkin et al., 1995).

One tool that has been used to investigate disability (which includes ID) is the Ten Questions Questionnaire (TQQ). The TQQ, developed as a part of the International Pilot Study of Severe Childhood Disability (Belmont, 1984), was the main tool frequently employed to evaluate disability in big populations (Stein et al., 1986). The findings suggested that the TQQ has good specificity for identifying severe forms of disabilities but it was found not to be an appropriate screening tool for mild-to-moderate degrees of disabilities. Of particular relevance to our study, a detailed review by Thornburn et al established that the TQQ was a suitable tool for assessing severe disabilities of all types except cognitive disabilities and tended to miss moderate degrees of intellectual disability (Thorburn et al., 1992).

Table 1: Comparing the Ten Question Questionnaire and the Wessex Behavioural Schedule

Properties	Ten Question Questionnaire (TQQ)	Wessex Behavioural Schedule (WBS)
What? Description	World Health Organization tool introduced in 1984 for identification of developmental disabilities in children in resource poor countries	UK tool developed in 1960s for assessing functional levels of ID adult persons for purposes of provision of services and rating profiles of need
Administration	The Researcher reads out questions to parents/caregivers	Parent, caretaker, professional or researcher
Number of questions	Ten Questions: 5 for cognitive abilities; 2 motor developments; 1 vision; 1 hearing; 1 seizure. Yes/response	15 Questions on a likert scale 1-3;two subscales of speech self help and Literacy(SSL):Social and physical Incapacity(SPI)
Psychometric properties studies in Africa	Sensitivity of 70% and specificity of 71.4% for moderate to severe cognitive impairment and positive predictive values of less than 33%	No African studies but in other studies, modest reliability reported

1.2 The Wessex Behaviour Schedule

The Wessex Behaviour Schedule (WBS) is a questionnaire developed in the 1960s in the UK for a study of ID in the Wessex region of England (Parker, 1975). A number of functional and behavioural questions completed by a parent, carer, residential worker or professional rated individuals on a number of skills and 'incapacities'. The WBS contains 15 questions and covers aspects of self-care, walking, continence, literacy, behaviour, vision and hearing (Kushlick et al., 1973). The authors used these items to categorize individuals according to two subscales - 'Speech, Self-help and Literacy' (SSL), and 'Social and Physical Incapacity' (SPI). The developers of the WBS did not establish clinical cut-offs for levels of impairment or disability. A subsequent evaluation of the reliability of the WBS by Palmer & Jenkins in 1982 showed that extremes on the WBS (very impaired versus no disability) had good inter-rater reliability, but that continence and behavioural items had relatively weak inter-rater reliability. The authors concluded that the WBS had 'modest but not negligible reliability' (Palmer, 1982). The authors commented that the WBS was a quick and easy to complete tool that might still be helpful in large-scale surveys to identify overall profiles of need.

Over the last few decades, the WBS has been used in a range of studies as a proxy for ID, for example, Richards and others in their studies of self-injurious and challenging behaviours have used it to measure intellectual disability (Richards, 2012, Oliver et al., 2012). However, to date there have been no studies that evaluated the psychometric properties of the WBS, including the internal consistency of items or the inter-relationships among the WBS variables. There have also to date not been any attempts to generate clinical cut-offs or screening cut-offs for the WBS. Whilst the WBS has therefore remained useful as a set of rated behaviours, it has not been possible to use the tool to categorize individuals into ID/No ID for larger-scale surveys to estimate intellectual disability.

1.3 Door-to-door survey of families in Khayelitsha

In 2013 a group of medical students from the University of Cape Town (M Amoni , S Dyantyi , D Lakhoo ,N Mgemane, and K Price) under the supervision of Prof Leslie London, School of Public Health, and in collaboration with Prof Colleen Adnams and Prof Petrus de Vries, Department of Psychiatry, set out to examine the prevalence of disability in Khayelitsha Township in Cape Town. Khayelitsha is a partially informal township in Western Cape, South Africa, located on the Cape Flats in the City of Cape Town and is estimated to have a population of about 444,080 (Cleary et al., 2006). The students aimed to generate an estimate of disability in Khayelitsha, to collect demographic data of factors potentially associated with disability, and to explore parental perceptions and knowledge about disability.

In consultation with the supervising team, the students opted to use the Wessex Behaviour Schedule (WBS), outlined above, as their main measurement tool. The study focused on parents/carers aged 18 and above. Only parents with children aged 5-18 years at the time of survey were included in the study. The sampling method chosen was random cluster sampling. Khayelitsha was divided into 26 clusters from which 4 clusters were randomly selected. From each of these clusters, a sample between 20 and 30 children participated in the study. To start the interview, a random house number was selected between 1 and 5, and then every 5th house was selected. If no one was home on the day or was not willing to participate, the next house was selected. The following 5th house was approached in case of another refusal. If the property had more than one housing establishment, the primary/main house was taken to partake in the study. In case of one primary caregiver being responsible for more than one child, each child in the age bracket of 5 to 18 years was included in the study.

The student research team collected data on n = 452 children and adolescents and estimated a rate of any type of disability of 19% (95% confidence interval 15.3-23.3%). The overall prevalence rate of 'disability' calculated from the study was very much in keeping with rates of

disability in LMIC identified with the TQQ in various studies (Lorencz and Boivin, 2013, Mung'ala-Odera et al., 2006).

In spite of the excellent methodological approach in terms of sampling method and sample size, the main challenge of the study was how to move from the prevalence of 'disability' towards an estimate of 'intellectual disability' as a subset of all disabilities. As outlined above, both the TQQ and WBS are measures of 'disability' in the broader sense. To date, there have been no clear attempts to see whether a measure of ID could be derived from the broader 'disability' scores. The psychometric properties of the WBS have to our knowledge not been evaluated. As such, no data are currently available about the internal consistency of the WBS, no previous evaluation have determined whether the WBS measures a unitary or multi-componential construct, whether there may be redundant items, whether there may be a natural factor for 'intellectual disability', or whether clinical cut-off scores could be derived from the WBS data.

1.4 The Minimal Difference Perceived 75% of time (MDP75), a new approach to determine minimum clinically meaningful difference in a scale or questionnaire

The MDP75 (Minimal Difference Perceived 75% of the time) is defined as "*the difference in the global score from a scale or a questionnaire which, 75% of the time, leads to the higher score being spontaneously attributed by patients or clinicians to the most severe situation*". The MDP75 can therefore be used to determine clinically meaningful cut-offs on questionnaires or rating scales (Falissard et al., 2003). In relation to a tool of adaptive behaviour, an MDP75 score would be the cut-off (overall value on the scale/questionnaire) where at least 75% of clinicians/experts would classify an individual as having an ID. If clinically meaningful cut-off scores can be calculated for the WBS, such cut-offs can be used to calculate clinically more accurate estimates of ID. In this study we attempted to use MDP75 approach to determine the cut-off point of the WBS.

2. CHAPTER TWO: LITERATURE REVIEW

In this chapter a review of the psychometric properties of the WBS, epidemiological studies of prevalence of ID in children and adolescents, and ID measurement tools is presented.

Mostly in LMIC, advancement and research in childhood disability has been critically trailing, (Maulik and Darmstadt, 2007b). The field of ID, which is the commonest developmental disorder (Maulik and Harbour, 2010, Dekker et al., 2002), particularly in children and adolescents has been described as a neglected one, especially in sub-Saharan Africa (Njenga, 2009, Adnams, 2010). Furthermore, most of these children lead a marginalized life as they suffer the dual jeopardy of disability and its associated stigmatization (Maulik and Darmstadt, 2007b) and high prevalence of both co-morbid psychopathology and physical illnesses (Einfeld and Tonge, 1996, Dekker et al., 2002).

There are a number of problems and challenges regarding the science of epidemiology to ID. These relate to how ID is defined, classified and how these definitions have changed over time. These as well as other differences in ascertainment sources and methods need to be considered when comparing ID prevalence over time and place (Leonard and Wen, 2002). Considerable methodological difficulties, particularly measurement instruments, facing researchers in the area of ID in children and adolescents may have contributed to the slow development of this field. The WBS is one of the scales that have been in use since the early 1960s in UK for screening for ID in adults. There is evidence that WBS continues to be used for ID screening even among children and adolescents (Oliver et al., 2012). However, very little is known about its psychometric properties, or about its use in other settings, including LMIC. Etiological factors, diagnosis and overlap of health conditions characterize definitions of childhood disability in scientific and policy contexts (Simeonsson et al., 2003). Likewise, a combination of the magnitude of impairments of body structure and function, limitations in activity and restrictions of participation often form eligibility definitions (Simeonsson et al., 2003).

Even in South Africa, like UK and USA, the above overlap is observed. Below are descriptions of legislation that demonstrate this dimensional overlap in South Africa:

South Africa ratified the UN convention on the rights of persons with disability (UNCRC) in 2007 and in Article 1 of the Convention, disability is defined as:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”

In 2006, the South African cabinet adopted the definition of disability (Erasmus et al., 2005) defined as *“the loss or elimination of opportunities to take part in the life of the community equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological, or other impairments, which may be permanent, temporary, or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society”*

Specifically for children, under the provisions of section 11(1) of the Children’s Act, in any matter concerning a child with a disability due consideration must be given to:

- a) *“Provide the child with parental care, family care or special care as and when appropriate,*
- b) *Make it possible for the child to participate in social, cultural, religious and educational activities, recognizing the special needs that the child may have*
- c) *Provide the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community, and*
- d) *Provide the child and the child’s care-giver with the necessary support services”.*

These two definitions from South Africa demonstrate that certified definitions intended to determine access to services frequently include multiple components of disability.

The two definitions reflect the social and medical models of disability. The International Classification of Functioning-ICF / UNCRC define disability in line with the social model of

disability instead of the medical or 'deficit' model. The pro-human rights social model definition, ironically, is associated with greater difficulties in accurate measurement of disability and intervention needs in individuals and populations, than the 'deficit' model. The WBS appears to assume the social model of disability.

2.1 Objective of literature review

The purpose of this chapter is to review and present a summary of the published literature concerning the prevalence estimates of ID in children and adolescents in Africa with specific aim of identifying methods of case ascertainment and psychometric properties of the instruments used. In addition, studies reporting psychometric properties of the WBS will be reviewed.

2.2 Literature search strategy

A literature search in a systematic way was conducted on 8th August 2013 and a repeat on 15th January 2016. Peer reviewed Journal articles related to this study topic were identified using PsychInfo and Pubmed databases. Particularly, those articles that reported on the prevalence of ID in children and adolescents 18 years and below, in Africa, published up until the date of search. Employing a multistage search strategy, the age group of interest was identified by use of the following keywords; *child**, *children**, *paediatric** or *adolescent**. The key words used in the search relating ID were: *mental hand cap**, *mental retardation*, *mentally subnormal*, *intellectual disability and learning disability*. *Epidemiology*, *Prevalence*, *incidence*, *cross-sectional study*, *population research and clinical samples* were the keywords used to identify epidemiologic prevalence studies. To identify studies in Africa, the keywords: *Africa*, *third world*, *developing nation and developing country* were used.

Furthermore, the researcher contacted experts in the field of ID to make sure that any supplementary studies that might be pertinent to the search were identified. Reference lists were studied for other potential reports and articles. The same strategy was used for studies

reporting psychometric properties of the WBS. Search terms included reliability, validity, sensitivity, specificity and Wessex Behavioural Schedule.

2.3 Selection of studies included in the review

The full publication was retrieved and examined if the headings and the abstracts supplied inadequate information. Studies in which participants were aged 0 to 18 years and were done in any African country were included regardless of the year it was done, sample size or instrument to determine prevalence of ID. This liberal approach was chosen in order to include as many studies as possible.

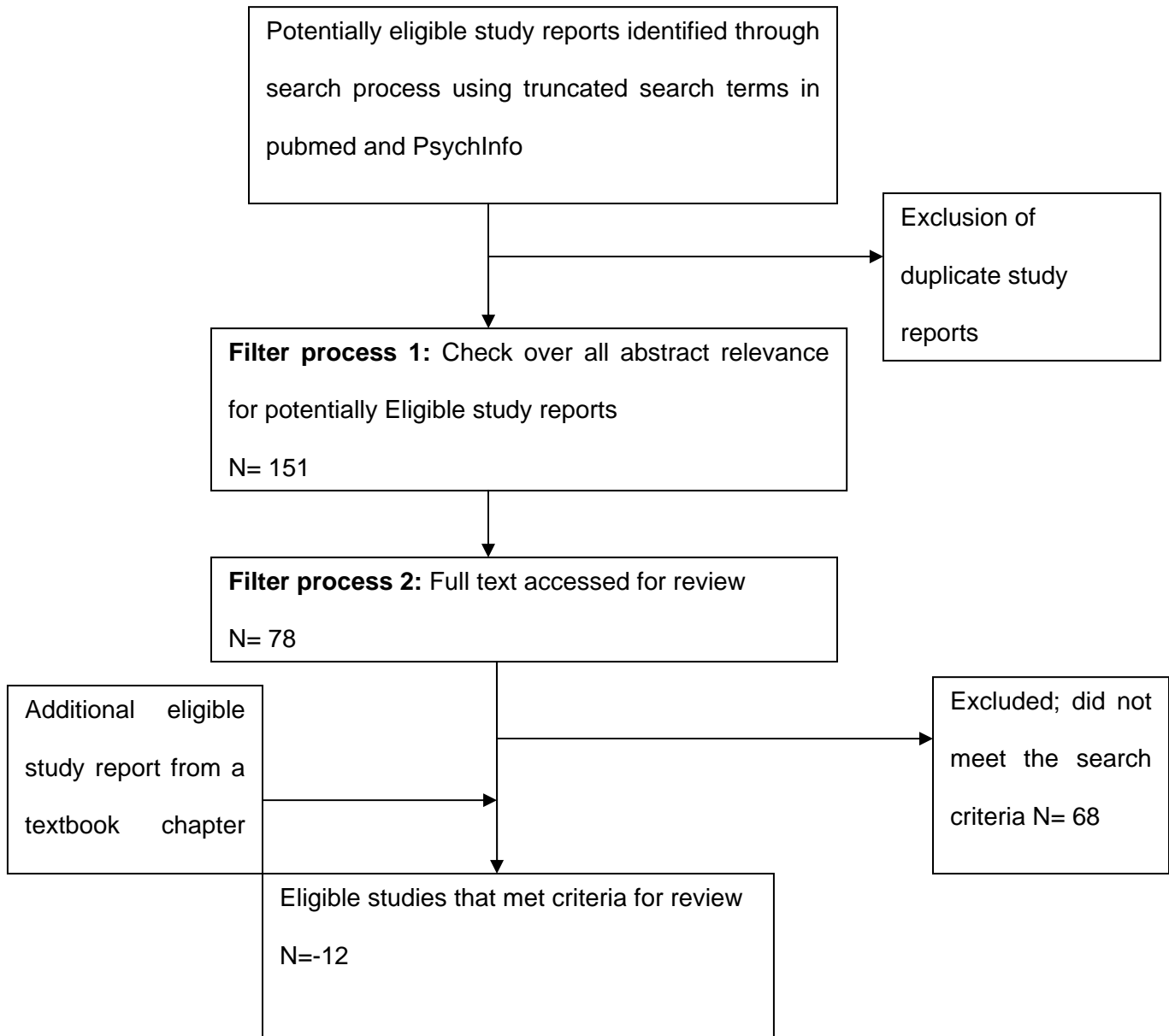


Fig 1: Flow chart showing steps taken in literature review

2.4 Results

2.4.1 Overview of literature

Using the above criteria, we retrieved twelve publications suitable for inclusion. The majority of studies were excluded due to not specifically reporting on the prevalence of ID in the patient sample. Of the twelve studies, two were clinical samples, seven community samples, two reviews and one chapter in a textbook. All were published in English. Regarding measurement tools for ID, Four studies were found that used the ten questions questionnaire (TQQ) and no particular studies for the WBS.

Table 2: Summary of retrieved publications included in the review

Study population and Titles of the studies	Author/year	Tools/Instrument	Psychometric properties reported	Informant	sampling methods	ID prevalence
Clinic samples						
The Pattern of Childhood Epilepsy with Mental Retardation in Nigeria	Iloeje S.O./1989	Clinical assessment	No	Parent	Consecutive enrollment	18/100
Childhood secondary (symptomatic) epilepsy, seizure control, and intellectual handicap in a non-tropical region of South Africa.	Leary P.M et al/1999	Clinical assessment	No	Clinical assessment	review of records	47/100
Community samples						
Children with ID in rural SA: prevalence and associated disability	Christianson, A. et al/1996	Ten Questionnaire	No	Parent		

"Serious" mental retardation in developing countries: an epidemiologic approach.	Stein Z et al/1996	Ten Question Questionnaire	No	caregiver	Stage 1: door to door Stage2: Neuro- developmental assessment	35.6 per 1000 Severe- 0.64 Mild-29.1
A study of the prevalence of severe mental retardation among colored children in an urban community.	Power DJ./1977	Undefined questionnaire	No	Parents/caregivers		1139 5.3
A study of handicapped children in a typical urban community in Cape Town.	Friedlander A, Power D./1982	Undefined questionnaire	No	Parents/caregivers	Door to door	2,64 and 3,36 per 1000 children
Pattern of disabilities in a residential school for the handicapped in Ilorin, Nigeria.	OlogeFE, Akande TM/2003	Undefined questionnaire	No	Records	Door to door	2,5/1000
Prevalence and risk factors of neurological disability and impairment in children living in rural Kenya	V Mung'ala-Odera et al/2006	Ten Questions Questionnaire	No	Parent		6.2% (

Learning disabilities among Nairobi school children	DhadphaleM,and B. Ibrahim/1984	Undefined psychological assessment	No	caregiver	stage1: Survey stage 2: clinical assessment	31/1000
Epilepsy and retarded growth in a hyper endemic focus of onchocerciasis in rural western Uganda.	OvugaE,et al /1992	Clinical assessment	No	Caregiver		
Prevalence of childhood disability in rural KwaZulu-Natal.	Couper J/2002	Clinical assessment	No	Caregiver		
Intellectual disability in rural black children in the Bushbuckridge district of South Africa.	Kromberg JGR, et al/1997	Clinical assessment	No	Caregiver	stage1: ten questions stage 2: clinical questions	17/1000

2.4.2 Prevalence of ID

2.4.2.1 Summary of published review papers

Before examining the twelve (12) studies identified in the search, the findings of the most recent review of ID in Africa will be summarized. The only published review that included all African countries was done by Frank Njenga (2009). He reviewed published literature and critically analyzed the nature and content of whichever novel information regarding ID in Africa in the previous 12-18 months prior to publication. Two papers from South Africa and one from Nigeria fulfilled the criteria set (Njenga, 2009). According to this review, one of the two included papers from South Africa (Kromberg et al., 1997a), contextualized ID by highlighting the traditional healers' potential role in management. Njenga concluded his review by stating that, *“of the many challenges facing persons with intellectual disability in Africa, high prevalence, discrimination, and access to justice and education needed to be key considerations”* (Njenga, 2009).

Colleen Adnams (2010) reviewed studies published from 2002 onwards with emphasis on the last 2-3 years prior to date of publication (Adnams, 2010). The review was confined to South African data available in the scientific literature but also included literature accessible on authorized South African websites on the services, epidemiology and policies for children and adults with ID. In her findings, she reported that there was limited published literature on ID in South Africa. She also noted that the not many epidemiological researches carried out before 2002 suggested that the prevalence rate of ID in LMICs was greater than in HICs (Adnams, 2010); This is consistent with the global meta analysis of Maulik et al (2011).

She also stated that there was small data describing ID geographically and across population and age groups, causing more challenges in identifying inequalities and differences in

distribution (Adnams, 2010). The reviews by Njenga and Adnams, though extensive, did not include commentary on the measurement tools used or their psychometric properties.

Although not solely an African study, Maulik et al (2007) carried out a review of 52 worldwide published literatures between 1980 and 2009 and estimated the prevalence of intellectual disability across all included studies. They reported prevalence of intellectual disability as 10.37/1000 population. They also established that estimates differed according to income group of the country of origin with the highest rates being from LMIC. Studies on child/adolescent population revealed the top prevalence of 18.30/1000 (95%CI 15.17–21.43) (Maulik and Darmstadt, 2007a). Maulik *et al.* also did not comment on measurement tools or their psychometric properties.

2.4.2.2 Studies included in the current review

The twelve prevalence studies of ID in children and adolescents in Africa included in the current review will now be examined further. There was no restriction on the publication date thus studies included those studies published to date. Since the subject of interest was psychometric properties of tools/instruments used to ascertain ID prevalence, studies that measured ID in children and adolescents regardless of whether they were clinical or community studies were included in the review.

Of the twelve studies, two were clinic samples (one from Nigeria and the other from South Africa) and ten community samples. Of the ten community studies, five were from South Africa, two from Kenya and Nigeria, Uganda, Zambia had one each. One clinical study from Nigeria was excluded because of few subjects in the age range of 11-20(Sunmonu et al., 2008). Of all the studies reviewed, only three used the TQQ, two used undefined questionnaires, and the rest used 'clinical assessment' to determine caseness of ID in their samples. We were specifically interested in studies that reported on the psychometric properties of the WBS or other

instruments used. However, none of the studies mentioned psychometric properties of the any tools used (See table 2 above).

2.4.3 Measures of ID and their limitations

In epidemiological studies of clinical entities like ID, the definition of a case is an important aspect. Over time, emphases on terminology and definitions of ID have gone through significant changes, leading to discrepancy in reported statistics and vagueness in research literature (Colmar et al., 2006). Operational and constitutive definitions of ID have been distinguished by Schalock and Luckerson (Schalock and Luckasson, 2013). An operational definition centers on the operations with which ID as a condition can be evaluated and measured. This definition of ID is used to diagnosis a person and therefore addresses the question of who is “in” and who is “out” of the category (Schalock and Luckasson, 2013). Basing on reviewed existing literature (Beadle-Brown et al., 2007, Brown et al., 2007, Schalock et al., 2010), the most regularly used operational definition of ID was advanced by AAIDD. According to this operational definition, *“Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”* (Schalock et al., 2010). Over time, the name or term has changed, an evaluation by AAIDD and APA shows that the important three elements of ID—limitations in adaptive functioning, Intellectual functioning and onset early in life - have largely remained the same over the past 50 years (Schalock et al., 2010, Schalock et al., 2007), (Schalock, 2011). A constitutive definition, conversely, defines the construct of ID and therefore helps both to shed light on the derivatives of the construct and to give a framework for practices, policies and research (Schalock and Luckasson, 2013). This definition of ID complies with the stipulations of deficits in human functioning, stresses on the disability understanding in line with multidimensional and an ecological perspective, and identifies the crucial role of individualized needs and supports in enhancing human functioning.

The constitutive definition of ID has an advantage, which is, it recognizes and emphasizes ID as complex both socially and biologically, by capturing the significant features or characteristics of individuals that are affected, establishing a framework that is ecological in nature, for support provision, and providing a firm base concept from where persons with additional developmental disabilities can be separately identified (Wehmeyer et al., 2008).

Regarding the assessment steps that are required for identifying individuals, three diagnostic criteria have been consistently used according to the operational definition of ID above: the significant deficits in adaptive functioning as expressed in cognitive, social and practical skills, the significant deficits intellectual functioning, and onset before the age 18 years.

Cut-off scores define adaptive behaviour and significant intellectual functioning deficits and interpretation made in reference to a statistical confidence interval (Schalock et al., 2010, Schalock et al., 2007). More distinctively, the criterion that has been used extensively since 1973 as a measure of “significant deficits in intellectual functioning,” in as diagnosing ID, is an intelligence quotient (IQ) score that is about two standard deviations below the population mean, putting the standard error of measurement (SEM) for the particular tools used into consideration, and the tools’ strengths and limitations (Schalock et al., 2007, Schalock et al., 2010). Similarly, the “significant deficits in adaptive behaviour” criterion for a diagnosis is performance that is about two standard deviations below the mean of either (a) a measure of social, conceptual, or practical adaptive behaviour or (b) an overall score on a standardized measure of social, conceptual, and practical skills (Schalock et al., 2007, Schalock et al., 2010).

The TQQ, that was provided from the International Pilot Study of Severe Childhood Disability, was the regularly employed tool to assess for disability in large study populations (Belmont, 1984) Further, a comprehensive review by Thornburn and others (Thornburn et al., 1992) established that for all types of severe disabilities, the TQQ was a good tool except for cognitive disabilities and it tended to omit moderate degrees of intellectual impairment. The TQQ does not

generate any cut-off values, but simply lists number components of disability in YES/NO question format (Thorburn et al., 1992).

In a study by Couper, the TQQ was modified by adding six more questions to recognize developmental impairments in two year old children. Although their revised version of TQQ was piloted before use, no reliability or validity evaluation was performed (Couper, ,2002).

In the above reviewed studies, none used psychological assessments or scales. In the review by Maulik et al (2011), they reported that studies based on the identification of cases by using standard diagnostic systems and disability instruments like the TQQ, showed lower prevalence compared to using psychological assessments or scales that showed higher prevalence. In their discussion, they stressed the significance of using standardized diagnostic systems to correctly and properly approximate the burden of ID. Four of the studies above used a two-phase design. The first phase composed of a house-to-house based screening of children by interviewing mothers or caregivers using a globally accepted questionnaire for identifying childhood disability in developing countries. Children who screened positive were enrolled into the second phase that involved a neurodevelopmental and paediatric assessment. Accordingly, in the majority of settings, the TQQ needs to be enhanced by another, more comprehensive assessment, including one or more disability-specific tools to capture a broader range of disorders and to help identify the degree of impairment.

2.4.3.1 Brief review of some of the current developmental/intellectual assessment tools

1) The Ages and Stages Questionnaire (ASQ)

The Ages and Stages Questionnaire is a standardized screener for developmental concerns in children from 4 to 60 months of age. Nineteen different questionnaires cover designated age intervals. Each questionnaire covers fine motor, gross motor, problem solving, communication, and personal social areas of development. Each sub-section is scored on a pass/fail basis.

Pediatric practices use this tool to learn about general development (Squires et al., 1995). In the studies reviewed, there is no evidence of the use of this tool in African context.

2) *The Child and Adolescent Intellectual Disability Screening Questionnaire (The CAIDS-Q)*

The CAIDS-Q was developed to help those who work with children and adolescents who are suspected of having an intellectual disability have a quick and easy indication of whether they actually do (McKenzie et al., 2012). The original authors report that it is valid and reliable and can be completed quickly with minimum demands on the individual, carer or professional completing it (McKenzie et al., 2013). The CAIDS-Q is reported to discriminate with high levels of accuracy between those who have an intellectual disability and those who do not (identifying those who have an intellectual disability with 97% accuracy), correlating well with adaptive functioning (McKenzie and Murray, 2014) and it does not require intensive and time-consuming assessment (McKenzie and Murray, 2015). CAIDS-Q can be used by professionals, families and carers in a range of settings, including health and criminal justice services. It can be completed directly with the individual or by someone who knows him or her well (McKenzie et al., 2012). The CAIDS-Q is currently being used to screen for ID in children with nodding syndrome in Northern Uganda.

3) *Vineland Adaptive Behavior Scales, Third Edition (Vineland-3)*

The Vineland-3 is an individually administered measure of adaptive behaviour. It is widely used in the assessment of individuals with intellectual, developmental and other disabilities. All Vineland-3 forms aid in quantifying adaptive behaviours in intellectual and developmental disabilities and other disorders, such as autism and Asperger Syndrome (Roizen et al., 1994, Fenton et al., 2003). The scales are organized using three domains (Communication, Daily

Living Skills, and Socialization) which correspond to the three broad domains of adaptive functioning specified by the American Association on Intellectual and Developmental Disabilities and by DSM-5 (APA, 2013). In addition, Vineland-3 offers optional Motor Skills and Maladaptive Behaviour domains for situations in which these areas are of concern. It is available in three administration forms online and on paper:

- Interview Form – completed by a professional who interviews a respondent (typically, but not necessarily, a parent) who can report knowledgeably on the adaptive behaviour of the examinee.
- Parent/Caregiver Form – is completed by a parent, caregiver, or other respondent who describes the examinee's adaptive behaviour using a rating scale format.
- Teacher Form – is completed by a teacher or daycare provider who describes the examinee's adaptive behaviour in the school (including preschool) or structured daycare setting using a questionnaire format.

The Interview and Parent/Caregiver Forms provide normative scores across the lifespan, from birth through age 90 +. The Teacher Form provides normative data for use with examinees ages 3 through 21. The examinee is reported on by a parent, caregiver, or teacher, but he or she does not participate in the assessment. Each form has a Comprehensive (full-length) and Domain-Level (abbreviated) versions of each form. Each of the forms can be administered online or on paper.

3) ***Kaufman Assessment Battery for Children, Second Edition (KABCII)***

The KABC-II is a measure of the processing and cognitive abilities of children and adolescents between the ages of 3 years 0 months and 18 years 11 months. It is organized into three levels (Age 3, Ages 4–6, Ages 7–18), the first two are appropriate for preschoolers (Kaufman and Kaufman, 1983). Bangirana and others studied the construct validity of the KABC-II in Ugandan

children aged 7 to 16 years with a history of cerebral malaria (Bangirana et al., 2009). They reported that five factors emerged after factor analysis comprising of subtests measuring Sequential Processing, Simultaneous Processing, Planning, Learning and subtests measuring immediate and delayed recall. They concluded that Ugandan children showed the KABC-II to have good construct validity with subtests measuring similar abilities loading on the same factor (Bangirana et al., 2009).

2.4.4 Conceptualization of intelligence and ID in Africa compared to Western conceptualization

There is hardly any assessment tool in Africa specifically designed to capture ID as a multi-dimensional construct. Most of the tools, e.g, the TQQ are general developmental assessment tools that evaluates the following developmental domains at varying levels - cognitive, language, motor, adaptive and socio-emotional (Sabanathan et al., 2015). These cannot be directly ascertained but are deduced through the performance of the child on a number of observed variables (test items). From the reviewed literature in LMIC, the frequently used approach to evaluate the developmental domains is completion of a questionnaire /verbal reporting about the child's abilities by parents which may be influenced by not only recall bias but also the way they conceptualize the constructs being asked. There are validated tests of general intelligence in Africa, particularly South Africa, but they are not usually generalizable to the population with moderate and severe ID, and they require specialized administration, which makes rigorous testing of general intelligence a scarce resource in Africa. By extension, this has implications for assessment of the cognitive aspects of ID.

Some studies done in Africa report that people in non-Western cultures frequently develop ideas in regard to intelligence that is fundamentally different from the ones that have shaped intelligence tests from the West (Benson, 2003, Serpell et al., 1993). Mundy-Castel in 1973 suggested that African culture tended to place a higher value on social than on technological

part of intelligence as compared to Western cultures (Serpell et al., 1993), and by extension, the cognitive difficulties of those with ID, may be seen through a lens of intelligence as a social construct instead of a scientifically measured cognitive one. In one study, Serpell and others reported that people in some African communities-especially in areas with limited Western schooling - tended not to distinguish between intelligence and social competence like the Western communities (Serpell et al., 1993). For instance, in rural Zambia, the concept of *nzelu* embraces cleverness (*chenjela*) as well as responsibility (*tumikila*) (Serpell et al., 1993). Parents from rural Africa would rather not separate the cognitive issues of intelligence from the social responsibility aspect, when they talk about their children's intelligence (Serpell et al., 1993). Sternberg and Grigorenko in the previous years have also investigated concepts of intelligence in Africa. Grigorenko and others, in rural Kenya among the Luo, have discovered that four gross concepts exist regarding the ideas about intelligence: *luoro*, including social qualities like respect, responsibility and consideration; *rieko*, which majorly corresponds to the Western idea of academic intelligence, but also may include specific skills; *paro* (practical thinking); and *winjo*, (comprehension) (Sternberg et al., 2001). Of the four concepts, *Rieko* is the one that is associated with traditional Western concepts of intelligence.

Thus due to differences in conceptualization of intellectual/cognitive functioning and lack of distinct division between this and social functioning, the dissection of ID from simple screening tools may be complex. In the Sternberg studies, he emphasized that lay theories of intelligence often lack the precision of scientific theories, but they can unveil on how intelligence is used by people in everyday life, propose fresh ways of research, and inform further on the issues regarding intelligence that have been ignored by scientific theories. Indeed, DSM-5 diagnostic criteria now have both Intellectual and adaptive functioning for intellectual disability.

2.5 Conclusion and motivation for the study

With this review, potential gaps that have been identified include: the methods used in ascertaining what a case of ID is, most studies used an unclear methods but a few used a two-stage process of door to door and then ten questions. Most studies report of general disability rather than specifically ID. In terms of classification, only severe ID is studied. The studies hardly reported associated factors with ID. None of the studies made statements about reliability and validity of the measures used in case ascertainment of ID.

Prospective investigators need not only tackle these gaps in current understanding and knowledge of ID but also move toward translating their research findings into public health policy changes that would have a positive influence in lives of children with intellectual disabilities in Africa.

2.6 Study aims

The main aim of this study was to explore the psychometric properties of the Wessex Behavioural Schedule (WBS) in an African context.

2.7 Study objectives

- 1) To determine the internal consistency of the WBS in relation to intellectual disability in 5-18 years old in Khayelitsha, Cape Town.
- 2) To examine the inter-relationships among the WBS variables using exploratory factor analysis
- 3) To estimate clinical cut-off point of the WBS to classify intellectual disability in 5-18 years old in Khayelitsha, Cape Town

3. CHAPTER THREE: DESIGN AND METHODOLOGY

3.1 Study design

The original Khayelitsha study was a cross-sectional, quantitative epidemiological study.

3.2 Study Population

The primary respondents in this study were primary caregivers, aged 18 and older (n=452) of children who were between 5 and 18 years old.

3.3 Sampling method

The sampling method chosen was random cluster sampling. Khayelitsha was divided into 26 clusters from which 4 clusters were randomly selected. From each of these clusters, a sample between 20 and 30 children participated in the study. To start the interview, a random house number was selected between 1 and 5, and then every 5th house was selected. If no one was home on the day or was not willing to participate, the next house was selected. The following 5th house was approached in case of another refusal. If the property had more than one housing establishment, the primary/main house was taken to partake in the study. In case of one primary caregiver being responsible for more than one child, each child in the age bracket of 5 to 18 years was included in the study.

3.4 Sample Size

Sample size was calculated using the online openinformatics. The estimated population of children and adolescents 5-18 years was 80,417; anticipated frequency of ID was 3%, confidence interval of 5% at confidence level of 95% gave a total sample size of n=382. Given that some households had more than one child, the actual number questionnaires completed was n=452.

3.5 Measurements

A structured interview was administered to the respondents (caregivers) with translators where necessary. The questionnaire (see appendix 1) was separated into two parts, one provided demographic and the other consisted of the WBS.

The following variables were measured in the questionnaire:

The caregiver: age, sex, relationship and household structure, mode of income, number of children under his/her care, understanding of ID, understanding of causes of ID, knowledge and usage of services in the area.

The child: For each child the WBS was completed on the three-point scale (1-3) as outlined in the WBS.

3.6 Inclusion and exclusion criteria

Only primary caregivers (18 years and older) of children between the ages of 5 and 18 were included in the study. Participants had to be resident in Khayelitsha, and at home during the data collection period (21 – 24th January 2013, between 8:30 and 16:00).

3.7 Safety considerations

Datasheets were kept in a locked cabinet in a locked office in the Division of Child & Adolescent Psychiatry. All master and copy electronic data files have been kept securely.

3.8 Secondary Data entry and analysis

In this study we performed secondary analysis of the data collected for the broader prevalence study as outlined above. All data were entered into SPSS and tested for normality. For continuous data that were normally distributed summaries using means and standard deviation were calculated. For non-normally distributed data, range and median values were calculated. For categorical variables, Chi-squared tests (X^2) were used if the each cell was greater than 5, and Fisher's exact test if smaller than 5.

3.9 Internal Consistency

Internal consistency reliability of the WBS was determined using coefficient alpha in SPSS.

3.9.2 Factor analysis

Exploratory factor analysis to establish several factors that could be employed to show connection among sets of interconnected variables of the WBS. This was carried out using SPSS.

Multi-collinearity: The determinant of R-Matrix to test for multi-collinearity was 0.001 which is greater than 0.00001 meaning that there were no variables that were extremely interrelated with each other. To verify the factor analysis assumptions, an assessment of the Kaiser-Meyer Olkin (KMO) test for sphericity measure of sampling adequacy was done and it suggested that the sample was factorable (KMO=.73). For the KMO statistic, Kaiser (1974) proposes values of 0.50 as the lowest; 0.50 to 0.70 are mediocre; 0.70 to 0.80 are good; 0.80 to 0.90 are great and values above 0.90 are superb (Hutcheson and Sofroniou, 1999). For this particular study, the KMO value was found to be 0.73 (see table 3 below), meaning the sample size was satisfactory for factor analysis. The KMO values for individual variables are produced on the diagonal of the anti-image correlation matrix. As for the rest of the anti-image correlation matrix, the off-diagonal elements represent the Partial correlations between variables. Bartlett's measure tests the null hypothesis that the original correlation matrix is an identity matrix. A significant test indicates that the *R*-matrix is not an identity matrix; therefore, there are some relationships between the variables to be included in the analysis. For these data, Bartlett's test was highly significant ($p < .001$).

The factor analysis method used was *principal factor analysis* also called *common factor analysis* because in our research question we are interested in the dimensions behind the variables. The precise rotation choice depended on the understanding of the relatedness of the

underlying factors. Since there are theoretical basis to believe that the factors in question are unrelated (independent), we chose one of the orthogonal rotations (the varimax).

Table 3: Kaiser-Meyer-Olkin (KMO) and Bartlett’s Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.734
	Approx. Chi-Square	3182.831
Bartlett's Test of Sphericity	Df	105
	Sig.	.000

3.9.3 The Minimal Difference Perceived 75% of time (MDP75)

Each completed questionnaire was entered into excel and exported to SPSS for analysis. MDP75 analysis was supported by Prof Bruno Falissard of Universite Paris-SUD. From the already entered data, 100 responses for the WBS was randomly selected, 10 in the range 0-10, 10 in the range 10-20, ..., 90-100. These 100 scales was grouped into 5 groups of 20 (group a, b, c, d and e). Four clinicians with expertise in ID were requested to rate the groups as follows:

Clinician 1 the WBS belonging to groups a and b

Clinician 2 the WBS belonging to groups a and c

Clinician 3 the WBS belonging to groups a and d

Clinician 4 the WBS belonging to groups a and e

All the clinicians were asked to respond with a ‘yes’ or ‘no’ to this question:

"Do you consider that the patient corresponding to this scale has a clinically significant intellectual disability?"

Estimates of inter-rater agreement were calculated from responses corresponding to group a and a cut-off point was estimated from responses for a, b,c,d and e.

For each cut-off point calculated for each clinician score, sensitivity and specificity was calculated and a Receiver Operating Characteristics (ROC) curve drawn.

3.10 Ethics

The research carried out was based on the principles of respect, confidentiality and beneficence with regards to the respondents. All participants provided written informed consent for participation in the study. For secondary data analysis, a submission to the Faculty of Health Sciences Research Ethics Committee was made. No further data was collected as part of the study, and no further contact with families was required. As such the risk to participants from this part of the study was therefore deemed to be minimal. The University of Cape Town, Faculty of Health Sciences Human Research Ethics (HREC) number was 223/2014.

4. CHAPTER FOUR: RESULTS

4.1 Sociodemographic characteristics

Four hundred fifty two (452) respondents were included in this study, with 246 (54.4%) being female. Age ranged from 5 to 18 years with a median of 10.00 years; mean 10.37; SD of 3.86. Four hundred and forty (97.3%) children were in formal education (including training centres, school of skills and special care centres) and just over 50% had biological mothers as primary caregiver. Figure 1 below shows the relationship of the child and the caregiver.

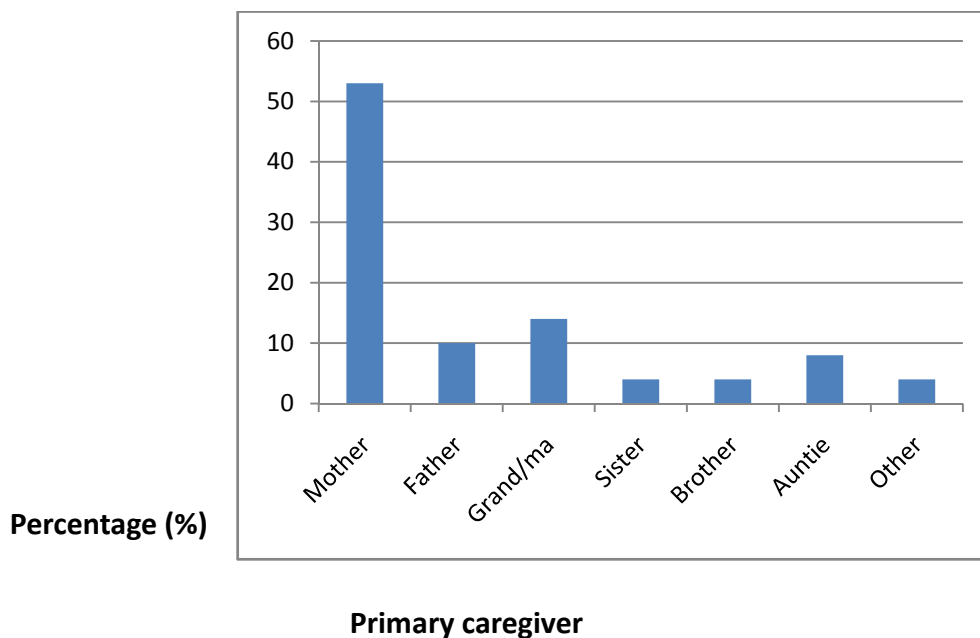


Figure 2: Child's relationship with primary caregiver

Twelve (2.7%) of these children were not in school, reasons for non attendance for this particular group was not captured, however, a general question was asked to all caregiver respondents: Do you know of any schools in your area that cater for children with intellectual disability? 72 % said they knew of a school for such children, these schools included: Naluthando, Tembalitha, Nolangile Primary School, Noceba and Khayelitsha school.

Table 4: Age of the child and the number in or out of school

Age of the child	In school	out of school
5	55	4
6	34	0
7	37	0
8	42	1
9	34	2
10	32	0
11	35	1
12	31	1
13	30	0
14	23	0
15	27	2
16	23	1
17	36	0
18	1	0
Total	440	12

4.1.2 Family characteristics

Over 60% of the households had between 1-3 adults living in the house and 57.7% children and adolescents below 18 years. There were as many married (39.6%) as unmarried (38.2%) parents. Figure 2 and 3 below show the age of the primary caregiver and household source of income respectively.

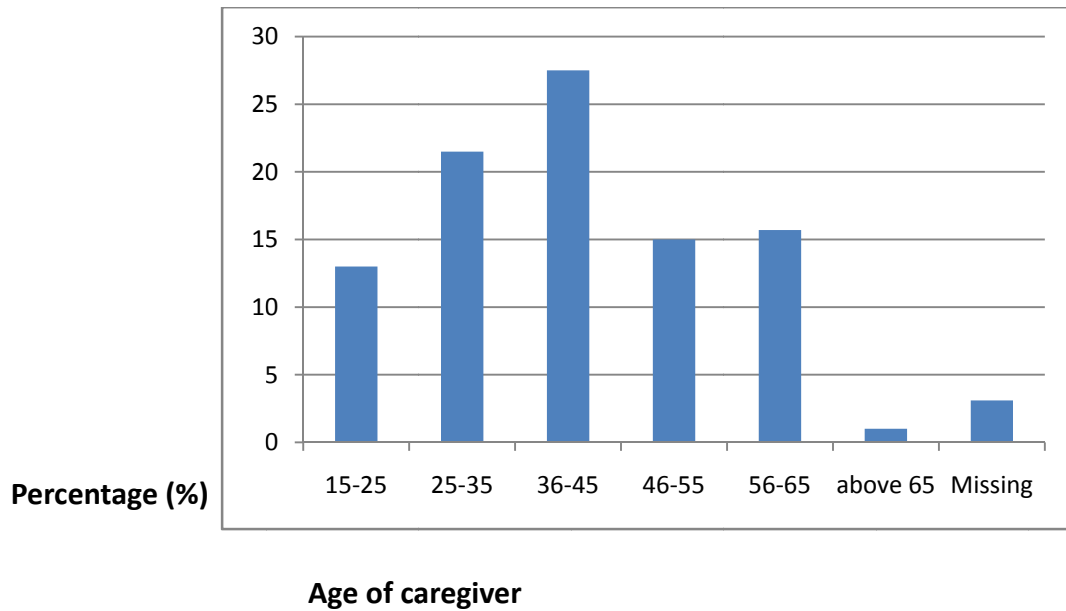


Figure 3: Age of primary caregiver

Household source of income: Nearly half of the caregivers in this study were on a social assistance grant and about a quarter were in formal employment. The figure below (Figure 4) gives the details of the household source of income.

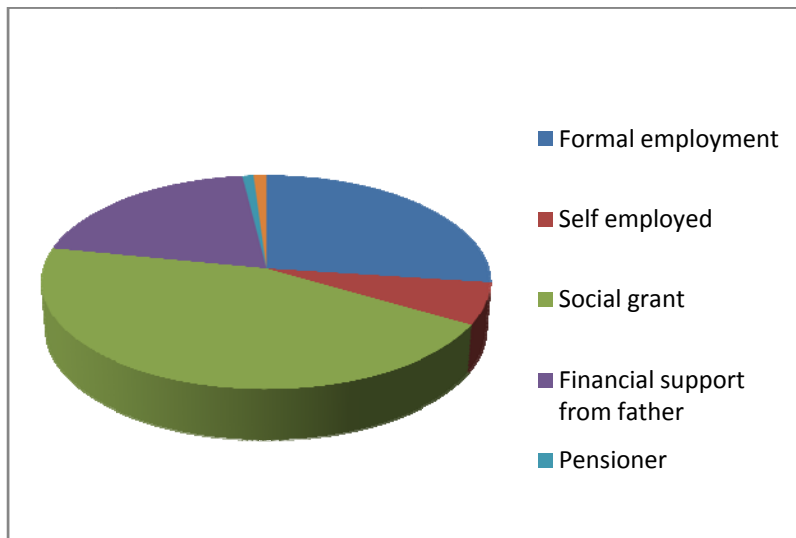


Figure 4: Pie chart showing household source of income

4.2 Psychometric properties of the WBS

The WBS was scored on a three-point (1-3) likert scale where 1 means a worse state. Given the 15 items, 15 was therefore the minimum score and forty five (45) the maximum score. This section describes results of some of the psychometric properties of the WBS. Results showed a mean score of 16.8, variance of 8.5 and standard deviation of 2.9.

4.2.1 Internal Consistency reliability coefficient of the WBS

The results below show the estimates of the reliability of the WBS scores on the basis of alternate configurations of the 15 items across a single administration of the WBS. Cronbach's alpha was 0.80. Conventionally, reliability coefficients range from 0.70 to 0.90. For a good test, the reliability should be 0.70 at lowest (Kline, 2000).

According to this study, the WBS has average inter-item correlation(the mean of all correlations) of 0.24 with each variable correlations that range from-0.03 to 0.89(table 1).The average inter-item correlation utilizes all of the items on the WBS that are intended to measure the similar construct. As illustrated in the table 5 below, a computation of the correlation between each pair of items was first carried out, For the 15 items, there is 105 pairings (see the coloured section of the table 3). As a statistical marker of internal consistency, utilization of the raw mean inter-item correlation is sometimes preferred to Cronbach's alpha (Neuendorf, 2003). The most favorable level of homogeneity happens when the mean inter-item correlation is in the 0.20 to 0.40 range (Briggs and Cheek, 1986, Clark and Watson, 1995)

Table 5: Inter-item correlation matrix of 15 items of the WBS

Inter-Item Correlation Matrix

Variable	Night wetting	Night soiling	Day wetting	Day soiling	Walk ing	Feed ing	Was hing	dres sing	visio n	spee ch	heari ng	sente nces	readi ng	writi ng	Count ing
Night wetting	1.000	.471	.535	.299	.061	.082	.308	.216	.129	.226	.275	.295	.300	.263	.283
Night soiling	.471	1.000	.553	.654	.185	-.030	.097	.206	.172	.252	.118	.345	.114	.114	.162
Day wetting	.535	.553	1.000	.458	.095	-.026	.135	.188	.260	.206	.303	.344	.145	.135	.183
Day soiling	.299	.654	.458	1.000	.229	-.014	.051	.113	-.024	.229	-.016	.117	.078	.089	.117
Walking	.061	.185	.095	.229	1.000	.404	.283	.229	.152	.325	-.022	.357	.196	.196	.221
Feeding	.082	-.030	-.026	-.014	.404	1.000	.488	.378	.032	.192	.201	.349	.249	.325	.274
Washing	.308	.097	.135	.051	.283	.488	1.000	.699	.015	.163	.159	.259	.475	.482	.436
Dressing	.216	.206	.188	.113	.229	.378	.699	1.000	.115	.263	.197	.333	.393	.374	.378
Vision	.129	.172	.260	-.024	.152	.032	.015	.115	1.000	-.034	.250	.167	.028	.034	.004
Speech	.226	.252	.206	.229	.325	.192	.163	.263	-.034	1.000	.104	.547	.196	.172	.248

Hearing	.275	.118	.303	-.016	-.022	.201	.159	.197	.250	.104	1.000	.347	.046	.009	.087
Sentences	.295	.345	.344	.117	.357	.349	.259	.333	.167	.547	.347	1.000	.250	.218	.202
Reading	.300	.114	.145	.078	.196	.249	.475	.393	.028	.196	.046	.250	1.000	.892	.698
Writing	.263	.114	.135	.089	.196	.325	.482	.374	.034	.172	.009	.218	.892	1.000	.762
Counting	.283	.162	.183	.117	.221	.274	.436	.378	.004	.248	.087	.202	.698	.762	1.000

4.2.2 Item-Total Correlation (corrected)

The correlation between a particular item and the sum of the rest of the items is shown on the third column of table 6 below. The information from this column is the fit between an item and the rest of the items in measuring a particular construct, in this case ID. From table 6 below, the best items appears to be conceptual items i.e reading, writing and counting with an item-total correlation of $r = 0.68$, 0.69 and 0.65 respectively. The item, Vision ($r = 0.13$) has the lowest item-total correlation.

4.2.3 Alpha values following deletion of an item

In table 6 below, if an item is not included in the calculation, the resultant values are shown in the column labeled 'Alpha if Item is deleted'. Therefore they reveal the adjusted Cronbach's alpha following a deletion of a particular item. It is expected that all values in this column should be around 0.80 as the overall alpha is 0.80. Values greater than the overall alpha are preferred as increase in alpha following a deletion of an item means improvement in reliability. In this study, deleting any of the items would not significantly change reliability of the WBS. The item 'vision' appears to be the worst as alpha would increase from 0.80 to 0.83 following its deletion. However this raise is not remarkable but also both values before and after deletion reveal a sensible level of reliability.

Table 6: Item-Total Statistics showing the Cronbach's Alpha if Item is deleted

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Night wetting	15.64	7.33	.45	.	.81
Night soiling	15.75	8.07	.35	.	.82
Day wetting	15.75	7.93	.38	.	.82
Day soiling	15.78	8.34	.24	.	.82
Walking	15.77	8.17	.34	.	.82
Feeding	15.74	7.87	.40	.	.81
Washing	15.59	6.87	.60	.	.80
Dressing	15.62	7.15	.57	.	.80
Vision	15.69	8.21	.13	.	.83
Speech	15.77	8.16	.36	.	.82
Hearing	15.74	8.18	.24	.	.82
Sentences	15.72	7.70	.47	.	.81
Read	15.43	5.99	.68	.	.79
Write	15.46	6.16	.69	.	.79
Count	15.55	6.581	.653	.	.792

4.2.4 Inter-relationships among the WBS variables using exploratory factor analysis

A Principal Axis Factor (PAF) with a Varimax (orthogonal) rotation of the 15 Likert scale questions from the WBS Schedule survey questionnaire was carried out on data collected from 452 participants.

4.2.4.1 Extraction

The factor extraction process involved first, determining eigenvectors (the linear components within the data set). This was done by calculating the eigenvalues of the R -matrix. The significance of a particular vector was determined by the magnitude of the associated eigenvalue, followed by application of a Kaiser's criterion to determine which factors to retain and which to discard. Factors with eigenvalues greater than 1 were retained.

Table 7 shows the eigenvalues linked with each linear component (factor) before extraction, after extraction and after rotation. Fifteen (15) factors were identified by SPSS prior to extraction. The eigenvalues associated with each factor correspond to the variance explained by that exact factor, and this is also displayed in terms of the percentage of variance explained. From the table, factor 1 explains 30.38% of total variance. The first few factors, particularly factor 1 explain reasonably large amounts of variance while subsequent factors explain only small amounts of variance. All factors with eigenvalues greater than 1 were extracted resulting in four factors.

The last column, *Rotation Sums of Squared Loadings* show the eigenvalues of the factors after rotation. Rotation has the effect of optimizing the factor structure, and one result for these data was that the relative importance of the four factors was equalized.

Table 7: The eigen values associated with each linear component (factor) before extraction, after extraction and after rotation: Extraction Method: Principal Axis Factoring

Total Variance Explained									
Factor	Initial Eigen values			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.558	30.384	30.384	4.154	27.691	27.691	2.821	18.807	18.807
2	2.295	15.301	45.685	1.936	12.909	40.600	2.007	13.379	32.186
3	1.540	10.266	55.951	1.100	7.334	47.934	1.829	12.191	44.376
4	1.327	8.843	64.794	.756	5.039	52.973	1.289	8.596	52.973
5	.965	6.435	71.229						
6	.957	6.382	77.611						
7	.679	4.529	82.140						
8	.563	3.754	85.893						
9	.455	3.033	88.927						
10	.414	2.761	91.688						
11	.395	2.631	94.319						
12	.323	2.154	96.474						
13	.230	1.530	98.004						
14	.209	1.396	99.400						
15	.090	.600	100.000						

Table 8: Factor Matrix before rotation

Factor Matrix ^a	Factor			
	1	2	3	4
Writing	.751	-.472		
Reading	.728	-.413		
Counting	.679			
Washing	.638			
Dressing	.605			
Sentences	.558			
Night wetting	.531			
Feeding	.454		.440	
Speech	.434			
Walking	.412			-.402
Night soiling	.472	.652		
Day bedwetting	.474	.586		
Day soiling		.537		
Hearing				.467
Vision				

Extraction Method: Principal Axis Factoring.

a. 4 factors extracted. 11 iterations required

The component matrix before rotation is shown in table 8, containing the loadings of each variable onto each factor. The many blank spaces for some loadings are explained by the fact

that all loadings less than 0.4 were suppressed in the output. The majority variables load very much onto the first factor before rotation. At this stage, one significant decision to make is the number of factors to extract. Employing Kaiser's criterion, SPSS has extracted four factors. However, this criterion is accurate when there are less than 30 variables and communalities after extraction are greater than 0.7 or when the sample size exceed 250 and the average communality is greater than 0.60. The communalities are shown in table 9 below, and only three exceeds 0.70. The average of the communalities is $(7.95/15 = .53)$.

Table 9: Communalities before and after extraction

Item	Initial	Extraction
Night Wetting	.443	.460
Night Soiling	.598	.705
Day bedwetting	.500	.639
Day soiling	.534	.606
Walking	.361	.409
Feeding	.433	.480
Washing	.627	.516
Dressing	.555	.431
Vision	.212	.118
Speech	.394	.301
Hearing	.297	.436
Sentences	.539	.508
Reading	.815	.807
Writing	.850	.917
Counting	.620	.612

Extraction Method: Principal Axis Factoring.

So, on both grounds Kaiser's rule may not be accurate. However, the sample size is relatively large as the research into Kaiser's criterion gives recommendations for much smaller samples. By Jolliffe's criterion (retain factors with eigenvalues greater than 0.70) we should retain 8 factors, but there is little to recommend this criterion over Kaiser's.

In addition, the scree plot was used as a final guide to decide on how many factors to extract. As shown in figure 5 interpreting this curve poses some challenges as it starts to tail off after three factors. However, another drop appears after four factors before a stable plateau is reached. Consequently, we could possibly defend retaining either two or four factors. Given the large sample size, we chose to retain four factors.

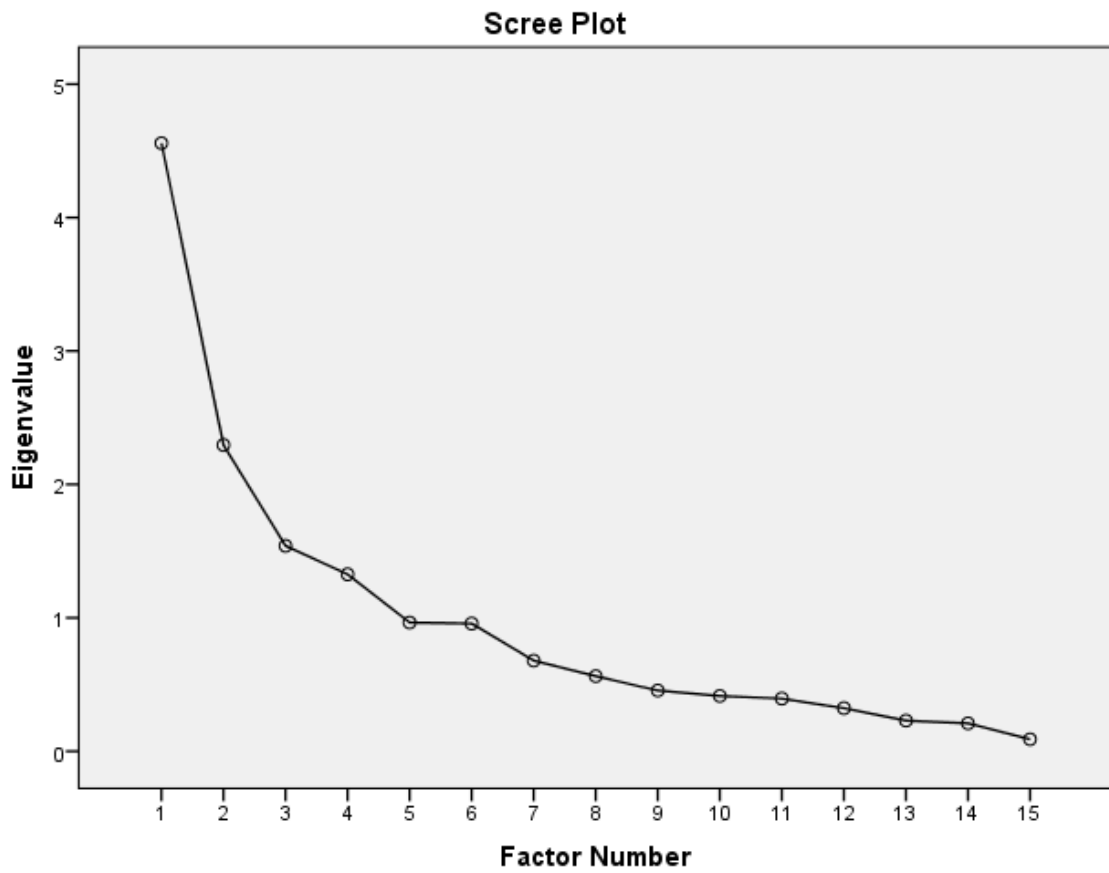


Figure 5: Scree Plot showing the relationship between Eigen Values and factor number

Table 10: Orthogonal rotation Varimax: Rotated Principal axis factoring

Rotated Factor Matrix ^a Variables	Factor			
	1	2	3	4
Writing	.943			
Reading	.883			
Counting	.747			
Washing	.504		.464	
Night soiling		.804		
Day soiling		.763		
Day bedwetting		.613		.500
Night bedwetting		.433		.425
Feeding			.617	
Walking			.605	
Sentences			.553	
Dressing			.461	
Speech			.461	
Hearing				.649
Vision				

Extraction Method: Principal Axis Factoring
 Rotation Method: Varimax with Kaiser Normalisation
 a. Rotation converged in 7 iterations

Table 10 shows the rotated factor matrix of the factor loadings for each variable onto each factor. The values are calculated after rotation; otherwise it is the same information as the component matrix in table 8 above. As mentioned above, Factor loadings less than 0.4 have been suppressed at the risk of leaving out possible significant loadings but the loadings greater than 0.4 signify substantive values. The output was sorted and arranged by size and therefore the variables are shown in the order of size of their factor loadings. Suppressing loadings of less than 0.4 and arranging variables by loading size eases interpretation of results.

Before rotation, a good number of variables loaded very much onto the first factor and the other factors didn't really get much loading. A clear picture was seen after rotation of the factor structure. Four factors came out with variables loading mostly onto one factor, perhaps with the exception of 'washing' that loads weakly (0.5).

After factor rotations, studying the content of questions that load onto the same factor and identifying common themes then followed. The variables that loaded very much on factor 1 appeared to relate to conceptual abilities except washing. The variables that loaded highly on factor 2 all seemed to relate to bladder and bowel control. The variables that loaded highly on factor 3 were feeding, walking, dressing, washing all seemed to relate to activities of daily living except making sentences and speech;. Finally, the variable that loaded highly on factor 4 was hearing but also day and night bedwetting. This analysis seems to reveal that the WBS may be composed of four scales: conceptual abilities, continence (bowel and bladder control), practical skill and sensory abilities. However, the authors of the WBS categorized its 12 items into Speech, Self-help and Literacy (SSL) and Social and Physical Incapacity (SPI) scale (Kushlick et al., 1973). From literature, it is not clear on what basis the categorization was done.

Factor Plot in Rotated Factor Space

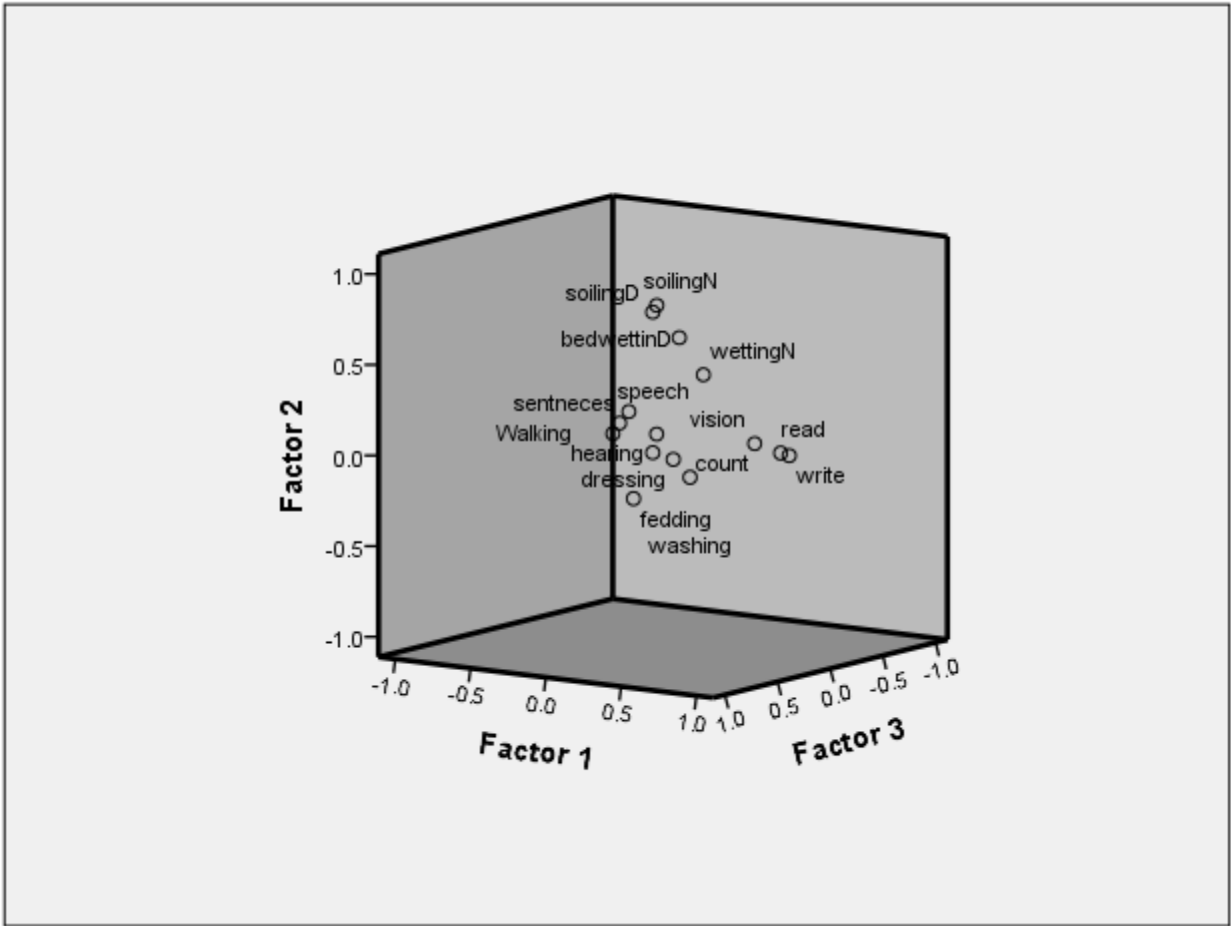


Figure 6: Factor plot in rotated factor space

The plot above shows the items (variables) in the rotated factor space and demonstrates how the items (variables) are organized in the common factor space.

4.3 Towards clinical cut-off values, MDP75 analysis

All the clinicians were asked to respond with a 'yes' or 'no' to this question: *"Do you consider that the patient corresponding to this scale has a clinically significant intellectual disability?"*

4.3.1 Inter-rater agreement

Online calculator for inter-rater agreement with multiple raters (Gwet, 2014, Hallgren, 2012) , was run to determine if there was agreement between four clinicians' judgement on whether scales belonging to 20 individuals had intellectual disability or not. For 20 scales, there were four raters with average of 18 years working in ID as clinicians and therefore 80 decisions were the outcome. Average pairwise percentage agreement was 58.33%; Fleiss'kappa of 0.08; observed agreement of 0.58 and expected agreement of 0.55 indicating slight agreement among the four raters on whether the individual had intellectual disability or not. Overall, raters therefore agreed only slightly more than chance.

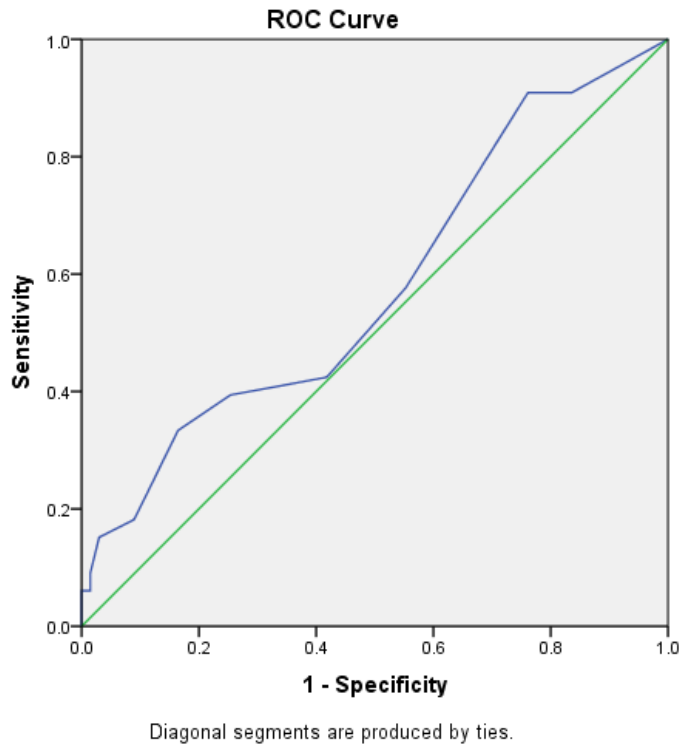


Figure 7: Receiver Operating Characteristics (ROC) Curve for the raters diagnostic evaluation

In order to estimate the trade off of sensitivity and specificity, the ROC curve was drawn and area under the curve (AUC) determined. The AUC measures overall ability of the test the WBS to discriminate between those individuals who have ID and those without ID. Out of the rated 100 cases, 33 (33%) were rated has having ID and 67 (67%) rated as not having ID. Under the non- parametric assumption, the AUC was 0.58, 95% CI (0.46-0.70); $p= 0.20$ and SE 0.06.

4.3.2 Coordinates of the Curve

Table 11: Test Result Variable(s):Coordinates of the Curve on the Wessex Behaviour Scale rating

Positive if Greater Than or Equal To	Sensitivity	1- Specificity
14.000	1.000	1.000
15.500	.909	.836
16.500	.909	.761
17.500	.576	.552
18.500	.424	.418
19.500	.394	.254
20.500	.333	.164
21.500	.273	.134
22.500	.182	.090
23.500	.152	.030
24.500	.091	.015
26.000	.061	.015
27.500	.061	.000
29.000	.030	.000
31.000	.000	.000

4.4 The difficulties the clinicians faced in rating the WBS

From the above results of ROC curve-AUC of 0.56, indicating that the WBS as a diagnostic test is nearly close to chance, a follow-up question to the raters was asked via email: “What made it difficult for you to rate the WBS?” The raters’ responses were analyzed qualitatively using the process of thematic content analysis which involved analyzing email comments, identifying themes within those data and putting together examples of those themes from the text (Pope et al., 2000). Thematic analysis which is related to phenomenology in that it focuses on the human experience subjectively. Emphasizing the participants perception, feelings And experiences as regards ID- allowing the participants to discuss the topic in their own words (MacQueen and Namey, 2012). Analysis was done basing on the theory that was already noted throughout literature review- deductive approach was used to arrive at the themes (Crabtree and Miller, 1999).

The researcher then read through all the responses several times to get familiar with the data. Coding (highlighting ideas, categories or themes) of the data according to the questions discussed would take place as the researcher read through the responses. This was done by placing expressions, lines or paragraphs (sorting) that described similar codes on the left hand side. Common themes or patterns that emerged were then placed together and interpreted (Abbo, 2011)

The themes that emerged were: age; inclusion of physical disability; limited information; and environmental factors.

Age

The younger the age the more challenging to decide whether a child has ID or not. The prediction of an intellectual disability is often difficult at younger age (less than 5 years) because the younger the child, the wider the standard deviations around “normal” development. That is, young children show a relatively large amount of variability regarding the rate and timing of the

achievement of milestones or skills, and this may or may not be predictive of later deficits or ability (Illingworth, 2013). One of the raters stated:

“The Wessex provides a list of functional skills which, when absent in an adult would make it much easier to make a clinical ID/no ID judgment. In a childhood population, as we were asked to rate, it gets more difficult the younger a child is. For instance, a 13 year old who does not dress, feed, write and wets the bed, one might with reasonable confidence (and I suspect inter-rater reliability) judge to have ID. However, if the same functional skills are absent in a 5-year old, the judgment is much more difficult, likely to need additional information and therefore more likely to lead to different ratings by reviewers” (Rater 3, 20 years experience).

Inclusion of physical disability

The raters agreed that although Developmental Disabilities are not only a cover expression that comprise of intellectual disability but it also encompasses other disabilities (e.g visual or hearing impairment) that are evident throughout the developmental period (childhood). Developmental disabilities emerge prior to 18 years of age, usually severe and persistent and likely to last a lifetime. A number of developmental disabilities are basically physical disabilities, for example epilepsy or cerebral palsy. A few people may have a situation that incorporates a physical and intellectual disability, for instance some genetic disorders. Intellectual disability incorporates the "cognitive" piece of this definition, that is, a disability that is largely identified with psychological and thought processes. Since intellectual and other developmental disabilities frequently happen together, ID professionals frequently work with people who have both sorts of disabilities.

Below is a quote that corresponds to the above theme:

“From my side, the most problematic issue pertains to the use of Wessex items around physical and sensory co-morbidities as part of a broader measurement of intelligence. Questions around enuresis, encopresis, blindness, deafness and mobility are not directly tapping into information

processing deficits and could confound assessment considerably” (Rater 4, 15 years of experience)

“Physical disability/mobility/sensory impairments may account for developmental delay. Hence, the Wessex will not necessarily provide putative evidence to conceptually link developmental delay with intellectual disability when delayed milestones are arguably better accounted for by physical disability in some cases”. (Rater 4, 15 years of experience)

Limited information

Both adaptive and intellectual functioning deficits are necessary for identification of Intellectual disability to be made. Inadequacy in intellectual functioning, including ability to plan, reason, abstract thinking, solve problems, make appropriate judgment, experiential and academic learning, as a matter of fact ought to be affirmed by clinical evaluation and individualized, intelligence testing standardized for that population. The outcome of deficits and Inadequacies of adaptive functioning are: falling below the developmental milestones for age, challenges in achieving socio-cultural standards for independent living and social obligation. Without continuous support, the adaptive deficits constrain functioning in at least one or more areas in day to day life like social participation, communication, and autonomous living, over various environments, for example, home, work, and group(Schalock et al., 2010).The quotes below support this theme:

“Diagnosing a child with ID should be done carefully and takes a fair amount of consideration of a number of factors. Even as a screening tool this doesn't provide enough information to determine if a child may or may not have ID” (Rater1, 6 years of experience).

“It seems to me the items have a focus on self-care, toilet training and academic skills. There is little in terms of social, language and other milestones or skills that might all be important to make an ID/Non-ID judgement call” (Rater 2,10 years of experience).

“As raters we might have had very different ideas about what was important to make a judgement using the information required or what weight to give to some questions. E.g. the speech question may have increased significance for some people but not for others. With many of the examples given you could give an argument that they might have ID (or a specific learning disability) but it's not clear where the 'bar' is for saying they might or might not have ID. There seem too many variables to do that in a clinically meaningful way”

(Rater 1, 6 years of experience).

Environmental factors

Globally and in literature, the commonest cause of ID has been reported to be inadequate nourishment and the child's environment that does not provide cognitive, emotional, moral and physical adequate support that is necessary for development and social adaptation in infancy and early childhood. (Tassé et al., 2012).

“For the questions Does your child feed him/herself; Does your child wash him/herself; Does your child dress him/herself (which I assume are trying to tap into a child's adaptive functioning/ self care/ daily living) I think that all 3 of these are problematic because once again there are other factors that could affect a child's ability to do these things...such as parents motivation/time to teach them and support them to become independent in these activities”(Rater 2, 10 years of experience).

Rater 3 had this to say:

“Academic skills - given that we know that the data were from a local South African population, I was very conscious of the possible educational opportunities the children received, particularly given their ages e.g 7 or 8 year old could not yet read, write or count...if this child had just started in school, had not yet been in school, or had a poor educational quality, my judgement about ID/non-ID becomes much more difficult”(Rater 3, 20 years of experience).

Rater 4 commented:

“With regards to efforts to say out whether the individual had ID or not, I found that it was also more difficult to get a sense of the child’s ability when he was younger than eight or even seven years. As you know, the development of reading and writing skills are contingent to many variables. This includes the quality of early education and access to the utilitarian resources required to obtain an acceptable level of competency. A by-proxy measurement of these skills therefore felt crude among especially younger children”. (Rater 4, 15 years of experience)

Suggestions by the raters regarding what could be done to improve the questions in the WBS

The raters suggested that, in the assessment, the clinician should ask questions in comparison to other children living in the same environment because normally intellectual functioning is assessed by means of norm-referenced IQ tests.

“There are no direct questions that ask whether the child:

- 1. Can learn to do things like other children of their age group and*
- 2. Whether they appear 'mentally slow' compared to other children of their age and*
- 3. Whether they comprehend/understand instructions given by the caregiver compared to other children of their age. Without these types of questions I found it very difficult to actually assess/extrapolate possible intellectual disability from this screen”* (rater 2, 10 years of experience).

Secondly, the raters also suggested making clinical direct observation and interview in addition to the use of the scale to make a diagnosis of ID:

“I would be very reluctant to 'diagnose' a child with ID without seeing them myself to piece together the qualitative and quantitative information. This tool provides little information for those filling in the form to give other relevant clinical or qualitative information. It also doesn't have

space for information not asked in this questionnaire. e.g. medical conditions, psychiatric diagnoses etc”(Rater 1, 6 years of experience).

Rater 4 had this to say:

“We need a screening measurement to augment clinical observations in scarce-resource settings. I found that the Wessex items focused on adaptive skills in communication, motor functioning, and activities of daily living. While these are commensurate with DSM-5 criteria of adaptive impairment in ID, my sense is that we need one or two additional items that measure fluid intelligence. Reviewers might have vacillated between different aetiological variables to explain adaptive impairments. Additional items that measured fluid intelligence have the potential to reduce some of the uncertainty by “triangulating” results from another angle”(rater 4, 15 years of experience).

5. CHAPTER FIVE: DISCUSSION

5.1 Introduction

In this study, we set out to explore the psychometric properties of the WBS in relation to intellectual disability in 5-18 years old in Khayelitsha, Cape Town, South Africa. We specifically set out to examine the internal consistency and inter-relationships among the variables, and made an attempt to generate clinical cut-off values for ID in this age group.

5.2 The Internal Consistency of the WBS

Internal consistency refers to the overall extent of inter-correlation of the items that make up a scale. The Cronbach's alpha was 0.80 and taking out any of the questions except hearing, vision and soiling resulted in lower alpha values. For these 3 items, corrected item total correlation values were low. Despite the theoretical concerns about bias, the internal consistency was good and no obviously depreciated items were identified. Problems with adaptive behaviour measures equally surface since assessment and information are usually collected from others (for example parents and/or teachers). Determination of the reliability of such information can be difficult. Sources of reliability problems include: items specificity and their underlying initial clarity (Colmar, 1988), memory problems, problems with comprehension of the inquiries that are asked and unconscious or deliberate bias either criticizing the kid's abilities or upgrading their aptitudes and skills. As Sattler (2002a) suggested, issues like expectations of an individual, frame of reference, and capacity to give data that is dependable and the chances they have or have not to carry out observations of the child in a variety of settings over different times, may affect the reliability of the findings(Sattler, 2002). In addition, it can be debated that adaptive behaviour assessments sometimes lack adequate attention to an informant's attitude to the child or motivation, as these factors could affect the responses

provided (Downing and Perino, 1992). Also, in this study, the respondent was ascertained by who was at home at the time of the interview visit and the interviewee may not have been the person in the household who had the most insightful knowledge of the target members of interest.

5.3: Factor Analysis

Cronbach's alpha measures internal consistency-a measure of scale's reliability and cronbach's alpha of 0.8 shows that the set of items in the WBS are closely related as a group. However, "high" value for alpha does not mean that the WBS is unidimensional. Unidimensionality and homogeneity demonstrate whether the items on the scale evaluate a solitary basic variable or construct (Clark and Watson, 1995). To check for dimensionality of the WBS, the researchers performed exploratory factor analysis. Only about 30% of the total variance was accounted for by the first factor signifying that the items on the scale may be multidimensional. Our analysis suggested that the WBS may be composed of four (sub) scales: conceptual abilities, continence (bowel and bladder control), practical skill, and sensory abilities. Sensory abilities were used to describe the fourth factor loading i.e hearing, day and night bedwetting for lack of a better phrase. The relationship between ability to hear and bedwetting needs further research, although reports of the association between sensory processing disorder and dysfunctional elimination syndrome in children have been documented (Lane, S. J. & Beaudry-Bellefeuille, I. 2015)

In order to function in their daily lives, all people need to learn adaptive functioning and behaviour, which is the collection of conceptual, social, and practical skills (Schalock et al., 2010). Three areas of adaptive functioning identified in *DSM-5* are Conceptual, social and practical. (APA, 2013).

- Conceptual skills: understanding language, how to speak, how to read, how to write, how to count, telling time, how to take care of math issues, the capacity to learn and recall data/information and abilities/skills.
- Social skills: interpersonal skills (e.g., how to make eye contact while tending to others), following rules (e.g., turn-taking during games), understanding others (e.g., empathy), social problem-solving (e.g., avoiding arguments), making and maintaining relationships.
- Practical daily skills: everyday *personal care* activities like dressing up, and grooming, feeding, appropriate use of the toilet; home activities like cooking, safety issues like looking both ways before crossing street, recreational activities school/work skills (e.g. showing up on time), and how to use money (e.g. paying for items at a store).

Conventional intelligence assessments have had a number criticisms leveled against it. This has led researchers and clinicians to move towards and place emphasis, importance and discussion on assessing adaptive behaviour. Because information obtained from adaptive scales provides information as regards the child's real practical ability and capacity to cope in everyday life, it is expected that they would have greater validity. These results suggest that the WBS does not measure the social parts of adaptive behaviour as currently defined (APA, 2013). Despite the general view that adaptive behaviour is critical to functioning and is among the new criteria for intellectual disability diagnosis (APA, 2013, Luckasson et al., 2002), there is still no consensus on the theoretical construct of adaptive behaviour (Jenkinson, 1996, Sattler, 2002) and its conceptualization and measurement construct are still emerging (Tassé et al., 2012).

Tasse summarized in his review article that factor evaluations conducted at the level of item and parcel have constantly conveyed a multifactorial solution. Prior to 1999, extensive works conducted on factor analysis have consistently revealed four factors. These factors are:

i) Motor or physical competence, which involves fine and gross motor skills, essential for feeding, ambulating, and toileting skills. One report of the study of the Client Development

Evaluation found out that the motor domain factor does not seem to hold in older children and adults (Harris et al., 1982). This factor seems to be more developmental in nature and may clear off as the child grows into middle childhood (8 years or 9 years of age) and may be more discriminating of physical limitations than intellectual disability; ii) conceptual skills, which include expressive and receptive language, writing and reading skills, and handling money; iii) social skills, which include friendships, interactions with others, social participation, social reasoning, comprehension, and reasoning; and iv) practical skills, which include household chores, dressing, preparing food, bathing, and washing dishes. The latter three factors constantly gotten from factor analytic work across many adaptive behaviour instruments and years is quite consistent with Heber's (1961) original conceptualization of maturation (practical), socialization (social) and learning (conceptual)(Heber, 1961).

Although children with ID are at a greater risk of bedwetting and soiling (Joinson et al., 2006), there are many factors that may be connected with bedwetting and soiling in childhood and adolescence (Elia et al., 2009). For example problems with emotions and behaviour, problems within the family e.g domestic violence or child or young person or family that is vulnerable, maltreatment of the a child especially if bedwetting is reported as deliberate or the child is being punished for bedwetting and undiagnosed metabolic disorders e.g diabetes mellitus (Nunes et al, 2010). This may explain why the loadings are on their own in this study.

In comparison with the commonly used Ten Questions Questionnaire (TQQ tool to screen for ID in LMIC, the TQQ was introduced in 1984 as a stop-gap to identify developmental disabilities in countries with low resources, in the non-availability of objective assessment tools and the dearth of skilled manpower (Durkin et al., 1995). However, just as the usefulness of TQQ has been overtaken by the fact that diagnosis of hearing impairment is recommended as early as at birth, infancy or toddlerhood for early intervention, having questions on sensory impairments in the WBS may not be warranted.

Social skills as measured by interpersonal skills, self-esteem, social responsibility, gullibility, avoids being victimized, follows rules and obeys laws, and social problem solving do not appear in the WBS as items and therefore no associated construct can be identified or observed as factor loadings. The original authors of the WBS used its items to categorize individuals according to a Speech, Self-help and Literacy (SSL) and Social and Physical Incapacity (SPI) scale (Palmer and Jenkins, 1982), but no particular questions to measure the construct of social skills.

One limitation common to screening tools for ID, including the WBS, is that although they recognize the presence or not of an ID, they do not tap into the extent or severity of the disability. Currently used screening tools thus have limited applications, especially in low resourced settings, in providing information on the nature of interventions that should follow positive screening for individuals with ID.

5.4 Attempts to determine cut-off points using MDM75

The initial aim of this study was to determine the WBS cut off points for diagnosis of ID in the age group 5-18 years but the inter-rater agreement was only slightly above chance agreement with average pairwise agreement of 58.33% with ROC curve almost close to chance. We therefore performed a post-hoc qualitative exploration to understand the possible reasons for the findings. From qualitative data, four subthemes emerged and these were: age, inclusion of physical disabilities, limited information and environmental factors. Preceding school entry, children may meet a wide variety of non-professionals and professionals who are the first to detect differences in the developmental skills of a child. This usually results to consultations with health professionals that then try to detect the cause, severity and possible trajectory of the developmental difference. In order to do this, the professionals try to differentiate between an isolated difference of development for example isolated speech delay and a more generalized delay for example, global developmental delay or likely intellectual disability. Unless in the

severe range, the prediction of an intellectual disability is usually difficult at this young age because the younger the child, the wider the standard deviations around “normal” development. That is, a relatively large amount of variability is shown by young children, in terms of, the timing and rate of the acquisition of milestones or skills, and this may or may not predict later deficits or ability. This broad range of “normal” makes it difficult to distinguish a delay, in the truest sense of the word, from impairment that is expected to persist. For example, even though most children that are finally diagnosed with a Communication Disorder displayed signs of language delay, the majority of children who gain language late are in due course not diagnosed with such a disorder, and by school-age, they advance to become indistinguishable from their peers (Maulik et al., 2011b, Durkin, 2002). In South Africa, ID is not often detected until the child enters formal education. Reasons for these are varied and may include lack of primary health centers, difficulty accessing referral pathways, long waiting lists for developmental clinics in public health system, children not attending preschools where they may be identified prior to grade 1.

Clinically, if a child is evaluated and confirmed to have generalized delays across more than one area of functioning, diagnostic options include Global Developmental Delay (GDD) and Intellectual Disability (ID). The decision-making process to determine which of these diagnostic labels should be applied to a child may be difficult one. As noted by the DSM-5, GDD “is diagnosed when an individual do not meet the required developmental milestones in several aspects of intellectual functioning” and when the individual is “unable to undergo systematic assessments of intellectual functioning”. An ID diagnosis is reserved for children that show shortfalls in intellectual functions (as established by standardized intelligence testing) and connected impairments in adaptive functioning. A GDD diagnosis will always require a reassessment, whereas ID may not. The reason for this is that ID is regarded as a more immutable, stable construct, whereas, GDD could potentially resolve. However, current

research recommends that only 20-30% of children with GDD diagnosis will not meet the criteria for an intellectual disability at school age (Shevell et al., 2005).

Another vital difference between ID and GDD is the age restriction. GDD can only be diagnosed in children under the age of 5. This is connected to the conceptual and practical challenge in reliably assessing cognitive skills in very young children (Sherr and Shevell, 2012). For children below the age of 2, developmental procedures do not predict future intelligence in typically developing infants (Fagan and Singer, 1983, Molfese and Acheson, 1997). That is, in part, because infant developmental measures tend to confound mental abilities with motor skills, language skills and play skills and other skills, and also as a result of the swiftness of maturational changes in the course of these early years. For children with delays, developmental measures such as achievement of developmental milestones have greater predictive validity, although significant changes in intelligence still arise. IQs are relatively stable by age 5, when investigating group norms, though individual differences may still be great (Sattler, 2002). However, this study took the age range of 5 to 18 in attempts to avoid the very young preschool children. The question of whether or not to diagnose children above 5 years with GDD where ID test are not possible remains a challenging one and every effort should be made to move away from this diagnosis to include or exclude ID at this stage.

The inclusion of physical disabilities has been discussed by others in critique of the worth of TQQ in connection to childhood hearing impairment. Most of the critique is in view of the growing number of developing countries that are at present striving to implement the World Health Assembly (WHA) resolution for early hearing detection and intervention (Hugo and Louw, 2006, Olusanya et al., 2005).

5.5 Environmental factors impacting on the use of the WBS as an adaptive scale

Existing tools and measures fall short in addressing contextual factors that may influence adaptive behaviour. These contextual factors may include mental illness in the primary

caregiver, socioeconomic status and amount of time spent in proper educational facilities (Arroyo and Zigler, 1995, Hart and Risley, 1999). The context, including people, material resources such as homes, educational and play items, activities among others, impacts on the adaptive behaviours that a child might learn at the outset and subsequently put across or express, mainly, noting that the provision of opportunities to practice a skill and respond appropriately is important (Greenwood et al., 1994). Consequently, it may be uncertain if the difficulty with adaptive skills is mostly as a result of child-specific factors, such as a diagnosed genetic disorder like Down syndrome, or with limitations of cognitive abilities that have stopped the child from learning or having the chance to engage in appropriate adaptive behaviours.

Neglecting to consider contextual and child-specific factors as influences on the acquisition (Colmar et al., 2006) and expression of adaptive behaviours implies that it may be impossible to know a particular skill is not displayed by the child. Thus, when evaluating the adaptive behaviour of a child with a likely ID, the child's present context and education history needs to be put into consideration, so that current status is evaluated in relation to chance to learn (Colmar et al., 2006). Further, Grantham and others in their review showed that absolute poverty is closely connected with poor educational and cognitive performance, most of whom are from Sub-Saharan Africa (Grantham-McGregor et al., 2007).

One of the earliest methods to categorize children with ID was suggested by Edward Zigler, in 1969. His categorization was based on the cause of their impairments, either organic or environmental. The former included children with identified causes of ID. For example, Down's Syndrome, these had dysmorphic features, IQ less than 50, medical defects and parents/siblings with normal intellectual functioning. The latter included children with no obvious origin of their ID, scored IQ between 50 and 70, had no dysmorphic features and no medical defects. Of particular interest, the group with identified causes of ID came from all socio-economic background while the group with no obvious origin of their ID came from low socio-economic background (Iarocci and Petrill, 2012)

Irrespective of whether ID and adaptive dysfunction is caused by well-known organic problem or environmental factors, the bottom line is that they all need a reliable tool that can identify them in order to be followed immediately with appropriate early interventions.

5.6 Study limitations

There are inherent challenges to working with secondary analysis, such as not having been part of the original study design team and not having all relevant background about rationale and aims of the original study. Fortunately, all supervisors involved in this project were part of the original study. Secondly, the study has a strong regional focus, being too population specific, within a local geographic community, namely, the study was carried out in Khayelitsha in Cape Town, thus the results may not be generalizable to other South African or other African populations. However, this information is vital for policy makers who must allocate educational, health and social support grants. The strong regional focus may not necessarily be considered a limitation and South Africa's varied socioeconomic and multilingual environment may necessitate a more regional approach to allow for adaptations to questionnaires.

Thirdly, the translation of the tool into Xhosa language may have compromised the internal validity of the WBS. Finally, we accept that we did not have any 'gold standard diagnostic tools for ID which could have allowed for external validation of the WBS.

Finally, The WBS was developed in the UK where schooling system is different. South African children only enter formal schooling at 6-7 years of age (versus 4 years in UK). Academic progress thus starts much later and this could have affected answers to the conceptual questions in the WBS.

6. CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

- i) Although the internal consistency reliability coefficient of the WBS was found to be high (Cronbach's alpha of 0.80), there was only slight agreement among the four clinician raters of 58.38%, and the ROC-AUC was 0.56 indicating that the WBS as a screening/diagnostic test is only fractionally better than chance in this developmental population. However, we acknowledge that the WBS may work fine in adult populations as previously reported.
- ii) Exploratory factor analysis suggested that the WBS may be a multidimensional scale with 30% loading on the first factor. The WBS may be composed of four subscales: Conceptual abilities, continence, practical skills, and sensory abilities, all of which may not directly be considered a measure of intellectual ability.
- iii) The difficulties in interpretation encountered by the clinician raters included a number of specific issues. Firstly, age - the younger the child, the more challenging to determine whether the child has ID or not. This is a result of the wider normal variations in development and the fact that the tool was not designed to be age specific. Secondly, the inclusion of physical disabilities like hearing and visual impairment that may or may not be related to ID. Thirdly, the WBS is limited in information even as a screening tool, given the current definition of ID that encompasses both adaptive and intellectual functioning. Finally, the WBS does not take into consideration the environmental factors like malnutrition and environmental deprivation during infancy and early childhood that may be the most common cause of especially mild ID, worldwide.

6.2 Recommendation

- 1) A combination of early assessments and interventions of children with ID may go a long way in increasing the percentage of children that realize their potential in development. Nevertheless, there is a need to have well-performing tools to identify children requiring intervention and for epidemiological research, since the accurate recognition of children and adolescents with ID is a prerequisite to taking action to minimize the impact of impairments. On the other hand, inaccurate assessment can result in considerable damage to children and their families.
- 2) The concerns arising from the clinician raters underscore the importance of getting assessment information from two or more informants, from two or more contexts, and to consider the informant's needs in relation to the child. In addition, the child's function should be described in relation to his or her same aged peers. Better and more accurate results may be achieved when scales are completed on the basis of clinician observations, information got from interviewing the child, caregivers and teachers where possible. However, we acknowledge that such an approach is no longer a quick and easy 'screen'.
- 3) Appropriate information should be included in the adaptive behaviour scales. The findings from the scale may give an overview of adaptive behaviours displayed by the child and the general level of support needed to learn and maintain skills, in addition to progress in development.
- 4) Investment in research and development of adaptive behaviour scales to enhance the performance of HIC existing tools like the WBS and their feasibility for application in LMIC settings is a priority if the benefits of researches to tackle intellectual disabilities are to be broadened to accommodate more children in LMICs.

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APPENDICES-QUESTIONAIRES

1. The Wessex Behavioural Schedule Questionnaire

These items refer to the person you care for. For each question (A, B, C, D etc ...), please enter the appropriate code in each box.

(Frequently=more than once a week)

- | | | | | |
|----------------------------|----------------|-------------------|---------------|--------------------------|
| A) <u>Wetting (nights)</u> | 1 = frequently | 2 = occasionally | 3 = never | <input type="checkbox"/> |
| B) <u>Soiling (nights)</u> | 1 = frequently | 2 = occasionally | 3 = never | <input type="checkbox"/> |
| C) <u>Wetting (days)</u> | 1 = frequently | 2 = occasionally | 3 = never | <input type="checkbox"/> |
| D) <u>Soiling (days)</u> | 1 = frequently | 2 = occasionally | 3 = never | <input type="checkbox"/> |
| E) <u>Walk with help</u> | 1 = not at all | 2 = not up stairs | 3 = up stairs | <input type="checkbox"/> |

and elsewhere

(note: if this person walks *by himself* upstairs and elsewhere, please also code '3' for 'walk with help')

- | | | | | |
|---------------------------|---------------------|--------------------------|-----------------------------|--------------------------|
| F) <u>Walk by himself</u> | 1 = not at all | 2 = not up stairs | 3 = up stairs and elsewhere | <input type="checkbox"/> |
| G) <u>Feed himself</u> | 1 = not at all | 2 = with help | 3 = without help | <input type="checkbox"/> |
| H) <u>Wash himself</u> | 1 = not at all | 2 = with help | 3 = without help | <input type="checkbox"/> |
| I) <u>Dress himself</u> | 1 = not at all | 2 = with help | 3 = without help | <input type="checkbox"/> |
| J) <u>Vision</u> | 1 = blind or almost | 2 = poor | 3 = normal | <input type="checkbox"/> |
| K) <u>Hearing</u> | 1 = deaf or almost | 2 = poor | 3 = normal | <input type="checkbox"/> |
| L) <u>Speech</u> | 1 = never a word | 2 = odd words only | 3 = sentences and normal | <input type="checkbox"/> |
| | | 4 = can talk but doesn't | | |

If this person talks in sentences, is his/her speech:

1= Difficult to understand even by acquaintances, impossible for strangers?

2= Easily understood for acquaintances, difficult for strangers?

3= Clear enough to be understood by anyone?

- | | | | | |
|------------------|-------------|--------------|------------------------------|--------------------------|
| M) <u>Reads</u> | 1 = nothing | 2 = a little | 3 = newspapers and/or books | <input type="checkbox"/> |
| N) <u>Writes</u> | 1 = nothing | 2 = a little | 3 = own correspondence | <input type="checkbox"/> |
| O) <u>Counts</u> | 1 = nothing | 2 = a little | 3 = understands money values | <input type="checkbox"/> |

2. The Sociodemographic questionnaire used in this study

Are you the primary care giver? <i>Ungumzaliwalomtana</i>	Yes	No	
What is your relationship with the child: <i>Yintoniubuhlobobakhonalotana?</i>			
How old are you? <i>Uneminyakaemingaphi</i>			
Relationship status:		Yes	No
	Single		
	Married		
	<i>Ushatile?</i>		
	Unmarried but living with partner <i>okanyenihlalanobabini?</i>		
	divorced/seperated		
How many people live in the household? <i>Bangaphiabantuabahlalaaphaendlini?</i>			
How many adults (> 18 years) live in the house? <i>Bangaphiabaneminyakaemi 17ukwenyuka?</i>			
How many children (<17 years) live in the house? <i>Bangaphiabaneminyaka emi16 ukwehla?</i>			
What is your source of income? <i>Nifumana phi imaliyophila</i>		Yes	No
	Employed <i>Uyasebenzaokanyaawusebenzi</i>		
	Self employed		
	Social grant <i>Uyafumanaigrantyomntanaokanyeeyabantuabakhulu (oyakho)?</i>		
	Financial support form father		
What is your understanding of ID? <i>Yintoni into oyaziyoungokukhubazekakwengqondookanyeingxakingengqondo?</i>			
What do you think causes ID? <i>Ucingabayintoniicause/nobangelalayalongxaki?</i>			
What help do you think a child with ID needs? <i>Ucingabangeziphiizintoabantwanaabanengxakiyengqondoabazdingayo?</i>			
Do you know of any schools in your area that cater for children with intellectual disability? <i>ZikhonaizikolozabantwanaabanengxakingokukhubazekangengqondoaphaeKhayalitsha?</i>	Yes	No	
If you had a child with intellectual disability, would you send them to a sepcial school? <i>UmzekeloUkubamtanawakhokunafumanisekaukubaunengxakiyengqondo, ungamsaeskolwenisabantwanaabanengxakiefananeyakhe?</i>	Yes	No	
	Reasons		