Neurodevelopmental screening accessibility: Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] inventory into isiXhosa and Afrikaans.

by

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Thesis presented in fulfilment of the requirements for the degree of Master of Arts (Psychology) in the Faculty of Arts and Social Sciences at Stellenbosch University

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April 2022

DECLARATION

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Date: April 2022

A note on the South African public healthcare sector:

"There are no data on children with disabilities or developmental delays. There are also no data on the numbers of children screened for disabilities and developmental delays" (Ilifa Labantwana et al., 2019, p. 18).

ABSTRACT

Background. Much of the current knowledge surrounding developmental disabilities stems from well-resourced, higher income countries. In addition, historic disparities in resource allocation have translated into a medical treatment gap for many communities in South Africa. In this context, where low mental health literacy has been indicated in the public healthcare sector, it is important to understand the factors that hamper effective child health and wellness detection. It is furthermore important to develop screening tools that enable such early detection of disorder.

Study Aims. I sought to translate and adapt the "Autism - Tics, ADHD & Other Comorbidities" (A-TAC) multi-domain neurodevelopmental screener into isiXhosa and Afrikaans, to overcome the lack of such South African comprehensive screens. I further sought to understand the perspectives and experiences of isiXhosa-speaking parents with regards to health screening and neurodevelopmental awareness.

Methods. The A-TAC underwent isiXhosa and Afrikaans forward- and back-translation, and source language comparison, before adaptations commenced with first-language speakers. Additionally, a purposively sampled group of 6 isiXhosa-speaking parents were recruited. Parents assisted both in the adaptation of the translated isiXhosa A-TAC, as well as participated in a focus group interview regarding perceptions of and receptivity to healthcare forms, mental health detection and child neurodevelopmental themes. Focus group input underwent thematic analysis.

Results. The A-TAC was translated into isiXhosa and Afrikaans and full, novel drafts of each screen have been produced. On the side of screening tool adaptation, 38% of Afrikaans items and 72% of isiXhosa items required significant revision to the original translations received. The current research produced a carefully deliberated set of adapted screen items in each language, with the isiXhosa version having additionally undergone focus group deliberation.

From thematic analysis, four themes of note arose. 1) Language barriers: a lack of isiXhosa in clinics impedes discussion and can result in shame for parents. 2) Healthcare disillusionment: a lack of capacity and privacy in clinics may dampen engagement with the healthcare system. 3) Conceptions of disabilities: developmental concerns may not be spotted, may be understood as arising from emotional turmoil in the child, may be synonymised with poor learning or intellectual impairment, or may be understood as the result of bewitchment. 4) Management

routes opted for: parents may choose inaction, or proactively pursue discipline, self-training, school support and healthcare support strategies.

Conclusion. Draft translations of the isiXhosa and Afrikaans A-TAC have been successfully produced, with recommendations for further contextual adaptation and testing proposed.

My research achieved its goal of unpacking parent perceptions surrounding healthcare detection and conceptions of Neurodevelopmental Disorders. Although discussion emerged within more of a biomedical framework, it highlighted barriers to healthcare service and the need for additional support avenues, including within the school environment. A novel element to emerge was the experience of language *shame* in the public healthcare setting.

Keywords. Neurodevelopmental Disorders. ESSENCE. Screening. Detection. Healthcare Provision. Parental Perceptions. Translation. A-TAC.

OPSOMMING

Agtergrond. Baie van die huidige kennis rondom ontwikkelingsgestremdhede kom uit lande met hoër inkomste en meer hulpbronne. Boonop het historiese ongelykhede in die toewysing van hulpbronne in baie gemeenskappe in Suid-Afrika gelei tot 'n leemte in mediese behandeling. In hierdie konteks, waar lae geestesgesondheidsgeletterdheid in die openbare gesondheidsektor aangedui is, is dit belangrik om die faktore te verstaan wat effektiewe opsporing van kinders se gesondheid en welsyn belemmer. Dit is verder belangrik om siftingsinstrumente te ontwikkel wat so 'n vroeë opsporing van ontwikkelingsversteuring moontlik kan maak.

Studiedoelwitte. Ek het ten doel gehad om die “Autism - Tics, ADHD & Other Comorbidities” (A-TAC) multi-domein neuro-ontwikkeling siftingsinstrument in isiXhosa en Afrikaans te vertaal en aan te pas, om die gebrek aan sulke Suid-Afrikaanse omvattende siftingsinstrumente te verminder. Ek het verder gepoog om die perspektiewe en ervarings van isiXhosa-sprekende ouers te verstaan met betrekking tot gesondheidsifting en neuro-ontwikkelingsbewustheid.

Metodes. Die A-TAC het isiXhosa en Afrikaans vorentoe- en terugvertaling ondergaan, en brontaalvergelyking, voordat aanpassings met eerstetaalsprekers begin is. Daarbenewens, was 'n doelgerigte steekproefgroep van 6 isiXhosa-sprekende ouers gewerf. Ouers het gehelp met die verwerking van die vertaalde isiXhosa A-TAC, asook aan 'n fokusgroeponderhoud deelgeneem rakende persepsies van en ontvanklikheid vir vorms van gesondheidsorg, opsporing van geestesgesondheid en temas vir kinderneurontwikkeling. Insette van die fokusgroep het 'n tematiese analise ondergaan.

Resultate. Die A-TAC is in isiXhosa en Afrikaans vertaal en volledige, nuwe konsepte van elke siftingsinstrument is vervaardig. Aan die kant van die aanpassing van siftingsinstrumente, het 38% van Afrikaanse items en 72% van isiXhosa-items aansienlike hersiening vereis van die oorspronklike vertalings wat ontvang is. Die huidige navorsing het 'n noukeurig oorlegte stel aangepaste siftingsinstrument-items in elke taal opgelewer, met die isiXhosa-weergawe wat addisioneel fokusgroepberaadslaging ondergaan het. Uit tematiese ontleding het vier noemenswaardige temas ontstaan. 1) Taalhindernisse: 'n gebrek aan isiXhosa in klinieke belemmer bespreking en kan skaamte vir ouers tot gevolg hê. 2) Ontnugtering in gesondheidsorg: 'n gebrek aan kapasiteit en privaatheid in klinieke kan betrokkenheid by die gesondheidsorgstelsel belemmer. 3) Begrippe oor kindergestremdhede: ontwikkelingsbekommernisse word dalk nie raakgesien nie, kan verstaan word dat dit uit spruit uit emosionele onrus by die kind, kan gelykgestel word aan swak leer of intellektuele gestremdheid, of kan verstaan word as die gevolg van betowering. 4) Bestuursroetes waarvoor gekies is: ouers kan onaktiwiteit kies, of proaktief dissipline, selfopleiding, skoolondersteuning en gesondheidsorgondersteuningstrategieë nastreef.

Afsluiting. Konsepvertalings van die isiXhosa en Afrikaans A-TAC is suksesvol vervaardig, met aanbevelings vir verdere kontekstuele aanpassing en toetsing voorgestel. My navorsing het sy doel bereik om ouers se persepsies van die opsporing van gesondheidsorg en die opvattings van NDD's uit te pak. Alhoewel bespreking meer binne 'n biomediese raamwerk na vore gekom het, het dit belemmerings vir gesondheidsorg en die behoefte aan addisionele ondersteuningspaaie, ook binne die skoolomgewing, beklemtoon. 'n Nuwe element wat na vore gekom het, was die ervaring van taal*skaamte* in die openbare gesondheidsorg opset.

Trefwoorde. Neuro-ontwikkelingsversteurings, ESSENCE. Siftingsondersoek. Opsporing. Voorsiening vir gesondheidsorg. Ouerpersepsies. Vertaling. A-TAC.

ACKNOWLEDGEMENTS

A thank you to all the people in my life who supported me in getting to this point. To my supervisor, Dr Zuhayr Kafaar, for the support, the encouragement and the flexibility shown throughout this entire process. It helped me always keep my eyes fixed on the goal. To all the dearest people in my life, for being my rock, for being my sounding board, for being spurring call to mission forward, and for statements as simple and well timed as “I back you”. Thank you.

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LIST OF ABBREVIATIONS

AAAQ	The 'Availability, Accessibility, Acceptability and Quality' Framework
ACE	Adverse Childhood Exposure
AD/HD	Attention-deficit/Hyperactivity Disorder
AD/HD-C	Attention-deficit/Hyperactivity Disorder – combined presentation/sub-type
AD/HD-PI	Attention-deficit/Hyperactivity Disorder – predominantly inattentive presentation/sub-type
AD/HD-PH/I	Attention-deficit/Hyperactivity Disorder – predominantly hyperactive/impulsive presentation/sub-type
APA	American Psychological Association
ASD	Autism Spectrum Disorder
A-TAC	The 'Autism – Tics, AD/HD and Other Comorbidities' Inventory
AUC	Area Under the Curve
CD	Conduct Disorder
CDC	Centre for Disease Control
DAMP	Deficits in Attention, Motor Control and Perception
DCD	Developmental Coordination Disorder
DoH	Department of Health
DoSD	Department of Social Development
DSM-5	The Diagnostic and Statistical Manual of Mental Disorders: 5th Edition
ECD	Early Childhood Development
EDA	Extreme Demand Avoidance
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations
LD	Learning Disorder
NDC	The Neurodiversity Centre
NDD	Neurodevelopmental Disorder
NDP 2030	National Development Plan 2030
ODD	Oppositional Defiant Disorder
PDD (-NOS)	Pervasive Developmental Disorder (Not Otherwise Specified)
SA	South Africa(n)

TD	Tic Disorder
WHO	World Health Organisation

1. INTRODUCTION

1.1. BACKGROUND

In sub-Saharan Africa and South Africa (SA), few statistics exist regarding the prevalence of childhood disabilities (Republic of SA (RSA) Department of Social Development (DoSD), 2015), much less for neuropsychiatric disabilities (e.g., Bakare & Munir, 2011; Bitta et al., 2017; Elsabbagh et al., 2012). Much of the information available *to* SA on Neuro-developmental Disorders (NDDs) stems from high-income countries (Springer et al., 2013), such as the Centre for Disease Control (CDC) (2022) in the United States. If European and Asian study samples are extended to the African context, researchers surmise that at least 10% of children experience some form of NDD (Gillberg, 2010; Hatakenaka et al., 2016a; Kadesjö, 2001). Furthermore, few *comprehensive* NDD screens have been adapted in SA, with existing ones centred on 1) rapid screening and/or 2) narrowed foci on individual conditions. This is concerning, as increasing evidence points to the overlap of NDDs as being the norm (Gillberg, 2010).

Additionally, intervention-provision is not uniformly accessible across SA. Owing to historic disparity in resource allocation, many communities experience a medical treatment gap (Braathen et al., 2013). Difficulties include a lack of facilities, over-worked and under-trained staff, and poor awareness around mental health difficulties (Bradshaw et al., 2006; Schierenbeck et al., 2013). This has further translated into difficulty in effectively adapting detection instruments for mental health conditions (Edwards & Steele, 2008). With this in mind, I seek to address both the spheres of NDD screening tool adaptation as well as barriers to effective screening. To do so, I have selected to adapt a comprehensive screening tool with which I have previously worked, the 'Autism - Tics, ADHD & Other Comorbidities' (A-TAC) (Hansson et al., 2005) inventory.

The A-TAC was developed at Gothenburg University, Sweden, and covers most domains of NDDs and associated psychosocial conditions (Larson et al., 2013). Furthermore, the tool has shown good to excellent scores of validity outside SA (see Section 2.7.2). Inadequate NDD management can have lasting impacts on the functioning of individuals, with a continuation and proliferation of impairments and psychosocial concerns (e.g., Carlsson et al., 2013; Gillberg, 2014; Plenty et al., 2013). It is thus imperative that screens are adapted for SA, and that barriers to access of screening and support are understood.

1.2. RATIONALE AND AIMS

The SA National Development Plan (NDP) 2030 asserts all children are entitled to adequate early developmental services, and that comprehensive intervention packages must be enacted for children with disabilities (RSA DoSD, 2015). This starts with *detection* and an understanding of the dynamics of detection, especially in spaces currently forced to work within the aforementioned treatment gap (Braathen et al., 2013). I sought to adapt the A-TAC into isiXhosa and Afrikaans, and to address the accessibility of NDD screening for Western Cape isiXhosa communities through first-language participant parents.

Aim 1: Translation work (Engaging with *supply*). My aim is to translate and adapt A-TAC screen items into isiXhosa and Afrikaans, towards the production of a linguistically and contextually informed, functional drafts for each. Translations of a comprehensive screen benefits SA healthcare-*providers*. This is also due to many existing, non-isiXhosa speaking health practitioners not being proficient in the language (Solomon et al., 2012), and thus there is a need for a means of obtaining accurate clinical data. I further use isiXhosa participant workgroups organised in collaboration with the Multi-Lingua (Language) School (MLS), to determine participant satisfaction with translated items. It must be noted that I will not establish construct validity or cultural equivalence of screen items.

Aim 2: Focus group work (Engaging with *demand*). My aim is to qualitatively investigate screen *recipient* perceptions of NDD detection. I seek to investigate the dynamics of SA health detection more broadly through thematic review of the input of participant parents. By means of a 1-hour focus group, I aim to understand parental perceptions regarding 1) receptivity to translated documents and screening forms, 2) experiences of child (mental) health detection and support processes as they stand, and 3) existing understandings of developmental disability.

The way these two groupwork processes inter-relate when exploring *demand* and *supply* factors of neurodevelopment detection is visualised in Chapter 4, Table 1. Although I do not pursue validity or reliability testing of the A-TAC, this study does produce an authenticated, translated screen that may be used in second-stage future research. Additionally, although SA cut-off scores are not derived for the A-TAC (and thus it is not confirmed to be 'predictive') – by design, only a portion of the screen serves 'prediction' (see Appendix H). The remainder of each

module builds supplementary insight into the clinical profile of a child, which is not deterred by a lack of validity testing, and which is bolstered by accurate translations.

The original aim was to include Afrikaans group processes in the adaptation of the A-TAC, with participants recruited from the Groot Drakenstein area. This is elaborated in Section 4.2.1. The longitudinal Drakenstein Child Health Study has indicated adverse environmental inputs impacting children in more under-resourced communities, with an influence on their health outcomes (e.g., MacGinty et al., 2020; Zar et al., 2019). The Afrikaans groupwork proved unfeasible due to COVID-19, and so Afrikaans A-TAC adaptation did not include groupwork processes. The adapted screen can be found in Appendix K.

1.3. RESEARCH QUESTIONS

The first study aim does not hold a specific question, and I instead look as far as possible to reach consensus on, and functional utility of, the meaning of translated A-TAC items. The focus group had three domains of query, as outlined in the Interview Schedule (Appendix D).

1. What is the input of participants on the A-TAC and its ideal administration procedures?
2. What is the nature of translated documents that parents receive in their communities?
3. What is the understanding of NDDs in the sample?

It should be noted the focus group followed a semi-structured model, and thus the results diverged within discussions. In this regard, discussion surrounding Question 1 quickly incorporated an overarching concern of language and service difficulties in healthcare centres. Thus, the original Question 2 became obsolete, as it grew clear there was a lack of such resources. In place of Question 2, and yet still in line with my rationale of investigating parent perceptions regarding healthcare screening, focus diverted towards unpacking healthcare and wellness detection difficulties in the community as an expansion of Question 1.

1.4. SIGNIFICANCE OF THE STUDY

Current SA research explores input from the perspective of parents of a *diagnosed* child (e.g., Guler et al., 2018). However, data is also required on parents who have not started such a therapeutic journey. The research participants do not, to their knowledge, have NDD diagnosed children. This means they could offer perspectives possibly insightful to the broader community narratives. Furthermore, I have translated a multi-domain, NDD screen into Afrikaans and isiXhosa, which contributes to future research and speculated current use for building insight into

a child. Finally, this study adds to existing literature concerning screen uptake barriers and healthcare detection difficulties. Although the A-TAC may not be appropriate for rapid, primary healthcare use when in its entirety, its segmentation into modules means it can be flexibly used.

1.5. DEFINITIONS OF KEY TERMS AND CONCEPTS

As they will be referred to throughout the paper, the following definitions must be explicated to provide a comprehensive conceptual and methodological context for the study.

1.5.1. isiXhosa Speakers

isiXhosa is part of the Nguni languages and is the second most spoken language in SA, as well as the most spoken African language in the Western Cape (Edwards & Steele, 2008). Although it is reductionist to speak of any one culture, dialect or circumstance for isiXhosa-speakers, some patterns are found. isiXhosa speakers demonstrate collectivism, with strong emphasis on the family unit, community cohesion and their relationship to God (Greeff & Loubser, 2008). Xhosa medical pluralism engages both Western biomedical and traditional customary intervention - with each being seen to have different strengths in recognizing and treating different conditions (Braathen et al., 2013; Khan & Kelly, 2001; Schierenbeck et al., 2013).

1.5.2. Neurodevelopmental Disorder (NDD)

An NDD (otherwise referred to as a developmental disability) is any neuro-psychiatric condition with typical onset in early childhood, with either known causes (such as Fragile X Syndrome) or unknown causes, that impairs a child's social, academic, and occupational functioning (American Psychological Association (APA), 2013; Gillberg, 2014). The core A-TAC modules that I sought to adapt focus on such NDDs.

1.5.3. Early Adverse Childhood Experiences (ACEs)

ACE is a broad concept referring to childhood traumas impacting the physical and mental health outcomes of individuals into their adulthood (Bellis et al., 2018). This study will use the concept of *early* ACEs, within the scope of neurodevelopment, to refer to adverse events and exposures that impact on the neurobiological development of the child. This includes teratogenic and toxic exposures (such as foetal exposure to alcohol), disease exposures and mechanical assaults (such as head trauma and neural inflammation) (e.g., Gillberg, 2014; Sarovic, 2019).

1.5.4. Autism Spectrum Disorder (ASD)

ASD is an NDD that predominantly impacts social understanding and engagement (both verbal and nonverbal), as well as comprises symptom of fixation, abnormal sensory sensitivities, and repetitiveness in behaviour and routine (APA, 2013). This also encompasses previous classifications of Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder (PDD) – not otherwise specified (NOS) (APA, 1994).

1.5.5. Attention-Deficit/Hyperactivity Disorder (AD/HD)

AD/HD is an NDD resulting in attentional difficulties, neural under-arousal, and concomitant impaired executive functioning, on one hand, and physical overactivity, emotional dysregulation and poor impulse control, on the other hand (APA, 2013; Gillberg, 2014).

1.5.6. Developmental Coordination Disorder (DCD) and Tic Disorder (TD)

DCD is an NDD comprising symptoms of dyspraxia, or abnormal motor functioning as seen in poor posture and clumsy or disorganised movement, proprioception, balance, or the physio-oral production of speech (APA, 2013).

TD is also a neurodevelopmental category of motor peculiarities, and reflects sudden, partially controllable, and repetitive actions, which may include vocalisations, motor movements or both (APA, 2013).

1.5.7. (Specific) Learning Disorder (LD)

An LD is an NDD in which an individual struggles with key tasks (and associated cognitive processes) considered core activities of the academic environment. Such impairment occurs in one or several of the domains of 1) reading, 2) writing, or 3) arithmetic (APA, 2013).

1.5.8. Co-morbidity

There is variability in the academic understanding of what constitutes co-morbidity of conditions. Least helpful is to view two categorical conditions existing simultaneously in the same individual with distinct symptomologies. Instead, comorbidity in this paper refers to the overlap and intermingling of two or more spectra of disorder. This results in unique symptom presentations and a blended clinical profile unique to each person (Gillberg, 2014).

1.6. STRUCTURE OF THE THESIS

Chapter 1: INTRODUCTION. This chapter presented the background, motivations, and objectives for the current study, whilst defining concepts found in the thesis.

Chapter 2: LITERATURE REVIEW. This chapter will present the literature that grounds the current study and will elaborate on the gaps. A description of isiXhosa communities is outlined, followed by the risks and conceptualisations around NDDs.

Chapter 3: GUIDING THEORETICAL FRAMEWORKS. This chapter outlines the various frameworks utilized in the study. This includes the APA diagnostic framework that grounds the A-TAC, an aetiological framework for NDDs, and social constructionism for data analysis.

Chapter 4: METHODOLOGY. This chapter outlines the protocols and procedures of the current study, both with regards to the translation and adaptation of the A-TAC, as well as the processes surrounding the qualitative focus group analysis.

Chapter 5: RESULTS AND DISCUSSION. This chapter outlines the A-TAC translation procedures, findings, and commentary. It will also provide a combined results and discussion outline of my thematic analysis.

Chapter 6: CONCLUSIONS. This chapter provides a concise summation and reflection on the results that were found in the study. Recommendations and limitations, as well as a concluding passage for the study overall, follows.

2. LITERATURE REVIEW

2.1. INTRODUCTION

The current study seeks to address and improve on the accessibility of NDD screening in SA by exploring the experiences and difficulties of health detection. Such investigation explores the perceptions of isiXhosa parents to derive themes of note towards detection procedures. In this chapter, I will discuss the current gaps in literature regarding NDD detection, prevalence and risk in SA and sub-Saharan Africa to motivate the need for a broad and comprehensive SA NDD screen. This includes discussion on SA governmental policy and priorities, and outlining the current conceptualising of different NDDs. I conclude this chapter with the developmental history of the A-TAC screen.

2.2. CONTEXT OF THE STUDY

As noted in Chapter 1, there is a noteworthy dearth of research into NDD prevalence and comorbidity, tailored screens, and diagnostic tools across sub-Saharan Africa, which makes asserting prevalence in SA difficult. This is partly owing to a lack of nationally standardised measures (Nel & Grosser, 2016).

2.2.1. NDD Prevalence in SA

An NDD prevalence review by Bitta et al. (2017) found that very few robust estimates are generated in low- to middle-income countries, with the bulk stemming from Asia-Pacific regions. They further found only two SA population-based studies suiting their criteria in the last 30 years. The first found rates for LDs (1,7%), seizures (0,4%), and struggles of perception (0,6%) in rural KwaZulu Natal (Couper, 2002). The second found epilepsy to be at a rate of 0,7% in the rural North East province of SA (Wagner et al., 2014). When looking at the limited number of studies within Africa, Bitta et al. (2017) found mean prevalence rates for AD/HD, LD, and motor impairment all at rates of less than 1% of the combined samples. Although, one cannot assume that all studies were methodologically aligned.

Conversely, a recent Ugandan population study found an NDD prevalence rate of 12.7% in the sample (Namazzi et al., 2019). Nonetheless, as the study was conducted with infants, prevalence was based on broad impairments in domains such as communication and fine and gross motor skills, rather than specific NDDs. When looking at ASD-related conditions in particular, a global review of prevalence rates found no population-level data on the African

continent within its criteria (Elsabbagh et al., 2012). Another African review found no specific attempts at ASD epidemiological studies, except in North Africa (Bakare & Munir, 2011).

The lack of epidemiological data is concerning because it clouds the extent, severity and overlap of symptoms. It thus obscures the trends found in clinical profiles. There is not a clear picture then of the problem-load and service provision needs in SA. This arguably leads to a lack of intervention priority and awareness raising or NDD support programmes. Furthermore, it leads to a failure to develop an encompassing view of the child. If the focus falls too much on one condition at a time, such as ASD *only*, service provision becomes incomplete and ineffective as only one aspect of the full clinical profile is being addressed (Gillberg, 2010). The need for a comprehensive scope of symptom overlap is vital in NDD screening and service provision.

2.2.2. Screening and Detection

Few SA screens have been validated to attend to the overlap of NDDs in children. Screen validation is the act of *ensuring* that a measure can accurately (and context appropriately) predict the absence or presence of specific conditions or skills (Gordis, 2009). For this reason, although the A-TAC has been used in Europe (e.g., Cubo et al., 2011; Mårland et al., 2017), further research must be done to ensure it performs well when adapted to SA recipients. Adaptation of the screen into isiXhosa and Afrikaans is the first step in providing a basis for validation studies.

In May of 2021, I conducted a cursory PubMed.gov search of SA developmental screen psychometric studies conducted since 2011. The search parameters were: *South Africa [mesh] AND (Mass screening / methods* [mesh] OR Neuropsychological Tests [mesh] OR Surveys and Questionnaires [mesh]) AND (Developmental Disabilities [mesh] OR Child Developmental Disorders, Pervasive [mesh])*. Surprisingly, only eight studies arose discussing psychometric properties. Of the three articles that discuss sensitivity and specificity, two are based on human immunodeficiency virus (HIV)-exposed infant clinical populations (Boyede et al., 2015; Knox et al., 2018). The third paper is a study investigating a subset of SA's very own 'Road to Health' developmental screening booklet, which demonstrated poor performance at detecting positive (present) concerns at only a 25% success rate (van der Linde et al., 2015). The preliminary validation that has been done in SA for screens of NDD concerns in HIV-exposed children are conducted in a causally known group of NDD infants. Thus, the sample does not necessarily apply to all NDD impacted populations.

More NDD screens do exist in SA, but they simply have more narrowed foci. Such is the case for: preliminary validation of the Modified Checklist for Autism in Toddlers (M-CHAT) (Stephens, 2012), several isiZulu-translated ASD infant screens (Chambers et al., 2017), and the Adult AD/HD Self-report Scale (ASRS) (Regnart et al., 2019) in a clinical patient sample. Furthermore, the Strengths and Difficulties Questionnaire has existing translations in Afrikaans and isiXhosa (de Vries et al., 2018; Goodman, 1997). Nonetheless, the construction of the screen is centred on internalising (emotional and peer concerns) and externalising (conduct and hyperactivity concern) domains, rather than emphasising core NDD modules as proxies for diagnoses, as is the focus of the A-TAC (Larson et al., 2010). Additionally, there have also been unsuccessful attempts at validating the Movement Assessment Battery for Children – Checklist (MABC-C), the MABC-2 and the Developmental Coordination Disorder Questionnaire'07 for DCD in Grade 1 samples (Milander et al., 2016a; Milander et al., 2019).

The trend in these screens is to focus on rapid and/or specific NDD detection. While rapid screening can be effective at a grass-roots level to aid in referrals for assessment, it holds little further utility in increasing the depth of clinician insight. Nor does it comprehensively guide which assessments should be pursued to ensure all domains of need are addressed in intervention planning. The intention behind adapting the A-TAC is that it comprehensively queries the symptom presentation of several conditions or domains of difficulty at once (Hansson et al., 2005), in line with the growing understanding that holistic assessment and intervention must be pursued towards the best therapeutic outcomes for the child (Gillberg, 2010).

2.2.3. Environmental risk factors for NDDs

There is no single cause for any given NDD. A combination of genetic susceptibility and ACEs interact and result in the altered or disrupted early development of the foetus or child (Sarovic, 2019). Such environmental risks include: 1) early exposure to teratogenic substances (e.g., maternal liquor, nicotine, recreational or medicinal drug use), 2) maternal stress and hormone imbalance, 3) malnutrition and vitamin deficiency, 4) head trauma or neuroinflammation to the infant, 4) birth prematurity or birth asphyxia, and 5) maternal immune activation or infant disease exposure (e.g., encephalitic or streptococcal infection) (Boivin et al., 2015; Gillberg, 2014; Sarovic, 2019, Sharma et al., 2018; Singh et al., 2015, Nel & Grosser, 2016; Richter et al., 2019; RSA DoSD, 2015). A further substance-based ACE, with applicability

to the SA farm working community, is maternal pesticide exposure, which may increase ASD risk, as well as the risk for comorbid intellectual impairment (von Ehrenstein et al., 2019). Intra-uterine assaults or infections result in the differential development of central nervous tissue (i.e., alter the development of the brain). This determines the boundaries of an individual's capabilities (e.g., functionally, socially, academically), and forms the base from which further development builds (RSA DoSD, 2015).

There is reason to believe a higher prevalence for NDDs exists in many SA communities than the surmised 10%, as many above-mentioned ACEs in lower-income settings (which impact epigenetic brain development) are more commonplace (World Health Organization (WHO), 2018). ACEs thus serve to instigate and aggravate the trajectories of NDDs. For example, disease exposure and drug treatments are possible risks for NDDs. In SA, there is a national plateaued HIV-infection rate of around 1/3 pregnant mothers (RSA Department of Health (DoH), 2015). This is derived largely from SA's most impoverished populations but may impact individuals across the socioeconomic spectrum. This is relevant, as in the Western Cape, uninfected children exposed to HIV and antiretrovirals (ARVs) demonstrate developmental delays, especially receptive and expressive communication (Wedderburn et al., 2019). Furthermore, infected children treated with ARVs also demonstrate continued communicative delay (Strehlau et al., 2016).

Stress and hormone imbalance, such as lower activation of the thyroid in pregnant mothers (which may also stem from excessive alcohol use), and in infants, result in adverse outcomes such as cognitive, motor and language impairments (Donald et al., 2018; Gilbert et al., 2012). Excessive alcohol use may further lead to the Behavioural Phenotype Syndromes encompassed by Foetal Alcohol Spectrum Disorder, with a noted prevalence in SA (May et al., 2017). In addition, chronic conditions, such as diabetes which is seen in 11.3% of the SA population (International Diabetes Federation, 2022), can impact on foetal neurodevelopment. This is evidenced by later impairment in cognition, executive functioning and perception, and an increase in the rate of AD/HD and concomitant behavioural difficulties (Daraki, 2017). Moreover, toxin exposures such as lead poisoning, and stress and violence (including intimate partner violence) (Boivin et al., 2015; Nel & Grosser, 2016) and pollution are common risk factors founds across SA communities (RSA DoSD, 2015). These may aggravate the

development of one or several NDD domains. This highlights the need for accessible, comprehensive, and once-off screening in SA.

2.2.4. SA Governmental Stance Regarding NDD Screening

Investigating comprehensive screens that are appropriate for SA and towards the betterment of developmental trajectories aligns with the SA Early Childhood Development (ECD) policy (RSA DoSD, 2015). This mirrors the WHO Nurturing Care Framework (WHO, 2018). Such policies intend to direct us toward *safeguarding* developmental trajectories, which includes the detection of problems and improving access to efficient intervention provisioning (WHO, 2018; RSA DoSD, 2015). Historical SA disparity in resource distribution has translated to difficulties in accessing or activating intervention routes (Ashley-Cooper et al., 2019). The SA ECD NDP 2030 maintains, and strives towards, a child's right to developmental support, including appropriate detection of concerns related to the child's age and stage of development (RSA DoSD, 2015).

The issue is that 'development' is an extremely broad term, only partially encapsulating NDDs, and improvements have not extended to all domains. The SA National Planning Commission in promoting the ECD NDP 2030 highlights 1) mother-infant health, 2) social service support, 3) nutrition, 4) caregiver support, and 5) early learning programmes to be the pillars on which the NDP 2030 goals are built (Ilifa Labantwana et al., 2019). This is fair and covers vital tasks such as safe delivery, vaccinations, social grants, nutritional supplementation, etc. Nonetheless, 27% of SA children under age 5 are indicated to experience stunted development (Ilifa Labantwana et al., 2019). Beyond this, there is no public sector data on the number of children with, or screening that occurs for, disabilities or developmental delays (Ilifa Labantwana et al., 2019). This makes assessing the progress of primary healthcare NDD intervention frustratingly difficult. The 'Road to Health' booklet is promoted in SA as ensuring all mother-infant pairs receive the same information and service enactment – but only demonstrates a 25% success rate in detecting developmental disorder concerns (van der Linde et al., 2015).

The overlap of NDDs and the need for multi-layered detection and intervention is also recognised by stakeholders of the SA DoH and DoSD. For example, in research on protocol *ideals* for screening, ASD-specific screening was, according to the stakeholders, not in line with

departmental priorities as it is not seen as an isolated condition, and a universal approach to developmental disabilities was proposed as being favourable instead (Franz et al., 2018). This is understandable, given resource constraints in the SA public sector. In addition to this, screen *translation* studies are specifically raised as a need (Franz et al., 2018). It must be said that a natural sphere of utility for the A-TAC is in the private sector, where there is greater time and capacity for comprehensive assessment. Additionally, not all A-TAC modules are centred on the early (under age 5) screening efforts which are the championed ideal. The current public sector NDD screening landscape has been neglected, and appropriate adaptation of the A-TAC screen may allow the tool to broach consideration for public sector use, even if in an abridged form.

2.3. COMMUNITY HEALTHCARE & RECEPTION TO NDDs

My goal is not only to ensure functional validity of the translated A-TAC forms, but also to investigate factors of relevance when it comes to healthcare detection processes, receptivity to adapted screens and perceptions of NDDs more broadly in a peri-urban isiXhosa speaking community. Given the lack of research that exists in this regard, points must be extrapolated from broader healthcare and mental healthcare research.

2.3.1. Mental Health Service-Provision in Xhosa Communities

The effectiveness of screening and intervention efforts is impacted by the context of their application. Under the legacy of racial segregation and historic channelling of resources to white communities in SA, general and mental healthcare in isiXhosa-speaking communities is, as a pattern, grossly under-provisioned (Ashley-Cooper et al., 2019; Braathen et al., 2013). Publicly accessible clinics tend to be nurse- or lay healthcare worker-managed, who are not effectively trained in mental healthcare and who experience a lack of clinician oversight due to resource and time shortages (Braathen et al., 2013; Bradshaw et al., 2006; Schierenbeck et al., 2013; Sorsdahl et al., 2012). As for the clinicians, less than 5% can consult with their clients in isiXhosa (Solomon et al., 2012), and this results in barriers to treatment and information when a diagnosis is made. Even though mental health difficulties (including affective, NDD-based, degenerative, psychotic, etc.) can result in a greater number of longer-term impairments, they are less detected and less treated than other concerns (Sorsdahl et al, 2012). This has resulted in propositions for a community care system for mental healthcare, with task-shifting towards non-specialist, volunteer applied interventions (Bradshaw et al., 2006; Sorsdahl et al, 2012). However, questions

regarding accessibility of services, efficacy and client follow-up are still a concern (Bradshaw et al., 2006).

2.3.2. Community Understandings of Mental Health and NDDs

This is complex and multi-faceted, as one needs to: 1) reflect on the mental health literacy of a community (including awareness of, cause of, and treatment for mental health concerns broadly defined), 2) reflect on the practice and provisions that surrounds mental health, and 3) one must reflect on the meaning made of neurologically based conditions specifically (and for NDDs, understanding surrounding the heritability of said conditions).

Mental health literacy, *both* on the part of patients and public clinic nurses, has been a clear barrier to effective treatment (Braathen et al., 2013; Kakuma et al., 2010). Xhosa patients are noted, by healthcare staff, to lack awareness of a range of different mental health disorders, including poor understanding surrounding proper medication use (Schierenbeck et al., 2013). Yet one cannot expect a member of the general public to be an expert in mental healthcare, and it has been noted by patients that clinic staff, in turn, provide no explanation or guidance with regards to the difficulties they are experiencing (Braathen et al., 2013). Such anecdotes include how patients are not given an indication of 1) what the concern is, 2) what the medication is for or 3) in some cases, additional or alternative routes to pursue intervention (Braathen et al., 2013).

This difficulty is amplified by the fact that the attending nurse is usually a general nurse who may not have the background (or even available time) to provide psychoeducation to a family (Braathen et al., 2013; Schierenbeck et al., 2013). For NDDs in particular, in SA there is a lack of awareness of NDDs such as ASDs, which leads to an unnecessarily long journey to diagnosis and intervention (Dixon, 2015). Unless occurring alongside an indicated syndrome (e.g., Down's Syndrome), NDDs are behaviourally assessed, and so are difficult to interpret (Dixon, 2015; Stephens, 2012). Even common mental health concerns go undiagnosed (Braathen et al., 2013).

Intimately related to the topic of mental health is stigma, whether anxiously anticipated, harshly received, or self-endorsed, as noted in SA individuals with Schizophrenia (Matshabane et al., 2020). Culture and stigma impact a parent's perception of their child's difficulties, and they may be shamed for bad parenting or a 'misbehaved' child, and in SA seek traditional, customary or ritual solutions for a possibly *bewitched* child (Dixon, 2015; Guler et al., 2018, Pillay et al.,

2020). Indeed, stigma and misinformation have been yet another repeated theme and pinnacle barrier to service provision in public healthcare (Schierenbeck et al., 2013; Sorsdahl et al., 2012).

It is not to say this cannot be addressed, as it has been shown that training of community healthcare workers led to greater insight, more holistic and humanistic modes of treatment, and greater strategic planning around intervention (Havenaar et al., 2008). A number of programmes are being implemented to target the impact of mental health stigma, including the South African Federation for Mental Health and the Mental Health Information Centre based out of Stellenbosch University (Kakuma et al., 2010). However, there are yet no effective means of tracking the grassroots impact of these programmes (Kakuma et al., 2010). Stigma stemming from traditional aetiological beliefs will be discussed in the next section.

Finally, the ‘neurological condition’ literacy and ‘genetic’ literacy of communities must be unpacked here, as these are core to NDDS. Considering this would be an under-researched domain of an already poorly researched field, it is necessary to look at the understanding that exists in isiXhosa-speaking communities regarding the heritability of difficulties more broadly. To this end, the examples I have used stem from studies regarding haemophilia (as a non-mental health, heritable concern) (Solomon et al., 2012), and dementia and schizophrenia (as neurologically based, genetically associated conditions) (Khonje et al., 2015; Matshabane et al., 2020). This produces mixed results for genetic understanding, with findings reporting either a poor grasp of the working of genetics in Xhosa families struggling with haemophilia (Solomon et al., 2012), to otherwise adequate, if nuanced, understandings of genetics held by Xhosa individuals impacted by schizophrenia (Matshabane et al., 2020). In the instance of haemophilia, complex processes of inheritance of genes related to missing blood clot agents carried by females and expressed by males may be difficult to communicate in isiXhosa (Solomon et al., 2012).

Overall, study participants have been able to relay an understanding of physical and behavioural traits being passed from parents to children, an awareness of dominant genes (even if this understanding does not align to conventional biomedical understandings) (Matshabane et al., 2020; Solomon et al., 2012), and a nuanced view of multiple moderating factors impacting on a person, such as culture, stress and social influences and additional environmental affronts such as drugs (Matshabane et al., 2020). When looking at dementia, aside from low awareness of dementia, the biomedical term holds a different meaning compared to the community-level

understanding of the term (Khonje et al., 2015). Lay constructs are culturally shaped and may reflect an understanding of causality (discussed in the next section), or otherwise take on an amorphous definition for multiple ailments in the elderly (Khonje et al., 2015).

2.3.3. Medical Pluralism

In addition to an emphasis on community, the cosmology of Xhosa people includes an emphasis on the role of ancestors in one's life (Khan & Kelly, 2001). Disorders may stem either from the displeasure of the ancestors or God (Khonje et al., 2015), or from antisocially motivated curses enacted by a witch (Khan & Kelly, 2001). The former may lead to stigma around mental disorders, as the individual's suffering is interpreted as self-imposed and requiring literal or symbolic self-cleansing (Khonje et al., 2015; Solomon et al., 2012). Community members seek help from both Western biomedicine and traditional healers to promote wellbeing, with both being either seen as different routes to deal with a concern, or otherwise with both respectively holding strength in different fields of concern (Braathen et al., 2013). As a traditional healer expressed to Braathen et al. (2013) himself, many conditions require him to cure curses, but not all disorders are caused this way. Both patients and nursing staff may follow along a pluralistic health model, with both branches being pursued (Braathen et al., 2013; Khan & Kelly, 2001; Schierenbeck et al., 2013). This may produce tensions when inconsistencies between the two branches of thought are brought to the fore (Kelly & Khan, 2001; Schierenbeck et al., 2013).

2.4. NEURODEVELOPMENTAL CONDITIONS

From a biomedical paradigm, NDDs refer to often genetically predisposed psychiatric disorders with typical onset in early childhood and an impact on nervous (and neuro-structural) system development (APA, 2013; Larson et al., 2013). NDDs lead to divergent development in neural-tissue connectivity and hormone systems, resulting in contextually 'atypical' behaviours compared to 'neurotypical' peers (Gillberg, 2015). Several comorbid disorders in a child require concurrent treatment (Singh et al., 2015). Thus, children with NDDs are at a higher risk of functional and psychosocial impairments throughout the lifespan, unless intervened on (Selinus et al., 2015). Though Chapter 1 introduced core NDDs for my study, it should be noted that additional concerns include intellectual disability disorder (IDD), borderline intellectual functioning (BIF) and encompassed diagnoses such as Behavioural Phenotype Syndromes or

Paediatric Acute-onset Neuropsychiatric Syndrome (Gillberg, 2015). However, as the A-TAC screen does not per se assess for these directly, they will not form a focus of further discussion.

2.4.1. Changing Conceptions

A key issue has been the tendency of psychologists to view psychosocial concerns as exclusive, categorical diagnoses rather than conceptualising them dimensionally (e.g., Anckarsäter et al., 2008; Larson et al., 2013; Mårland et al., 2017). This is shifting, as seen in Gillberg's (2010) notion of ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations); stating that NDDs often occur in the presence of, and in interplay with, others. NDDs, at their root, are the result of divergent nervous system development that results in a plethora of different brain structures, aberrant connectivity and heterogenous symptom profiles (Licari et al., 2019). In this context, overall brain development may result in a convergence of symptom domains (i.e., an 'overlap' of symptoms and conditions based on shared neural networks, for any sphere of functioning) (Licari et al., 2019). This is relevant, as the co-existence of two or more disorders is more common than singular, 'pure-form' conditions (Larson et al., 2013).

Indeed, the concept of ESSENCE posits that a child diagnosed before the age of five with an NDD will likely manifest with comorbid psychiatric and psychosocial concerns, which also impact on the severity and course of the 'primary' diagnosis (Gillberg 2010; Selinus, 2015). For this reason, intervention only focused on combating a single symptom-cluster rather than a holistic view of the child would be 'inappropriate' (Gillberg, 2010). Thus, a multidisciplinary, broad, socio-medical approaches must be utilized for each child entering clinical services (Hatakenaka et al., 2016a, Selinus, 2015), and appropriate screens should form the first point of assessment.

In addition, it has also been noted that NDDs appear normally distributed within the population and should be seen as "lowermost extremes of […] neuropsychological abilities" (Anckarsäter et al., 2008, p. 5). This is in opposition to viewing diagnoses as binary markers of either being 'pathological' or not. Furthermore, the presentation of NDDs is not stable over time, which may lead to diagnostic 'drift' or substitution between conditions (Lundström et al., 2015; Selinus, 2015), such as occurs when awareness for a condition is raised.

2.4.2. A Brief Outline of A-TAC NDDs

An important element of adapting an NDD screen is understanding what each domain of concern entails.

2.4.2.1. Autism Spectrum Disorders and Communication Disorders

ASD is a heterogeneously presenting deficiency in pragmatic-communicative skills, management of social-dynamics and cognitive flexibility (Sharma et al., 2018). It is usually assessed via standardised frameworks such as the Diagnostic Interview for Social and Communication Disorders (Wing et al., 2002). DSM-5 criteria (APA, 2013) relate to:

- **Impaired social communication**. The individual may show contextually inappropriate communication (e.g., bluntness or lack of eye contact), delayed language development and poor insight into the non-literal or -verbal. The child may lack insight into the motivations and perspectives of others or may demonstrate poor reciprocity or joint-cooperation (APA, 2013; Sharma et al., 2018).
- **Inflexibility and fixations**. The child may insist on uniformity, repetition, routine, or other behavioural rituals – or otherwise intensely circumscribed interests (APA, 2013). Additionally, a new sub-domain is that they may have peculiar processing of sensory stimuli (either hyper- or hypo-reactivity) (APA, 2013; Marco et al., 2011). The individual may either be oblivious to, or extremely perturbed by, seemingly banal stimuli – and become distressed when 'over-loaded' with multiple sensory inputs (Marco et al., 2011).

Theories for ASD include a lack of sufficient 'Theory of Mind' as a meta-representational capacity; and thus, individual fail to conceptualise or predict the independent thoughts of others (Baron-Cohen et al., 1985). A second theory posits an information-processing impairment, whereby the individual lacks the ability to abstract 'prototypes', and thus to draw on pattern recognition and associative-networks in future circumstances (Fabricius, 2010). A final theory suggests a common neurological disruption with regards to social information processing (Pelphrey et al., 2011). None, however, manage to encompass the full heterogeneity of ASD (Waterhouse, 2013).

Mild to moderate ASD, in the absence of comorbidities, is overall not found to be particularly impairing and often will go largely undiagnosed. It is the addition of supplementary concerns such as language delay and mutism, poor intellectual functioning, and additional

neurodevelopmental symptoms such as motor dysfunction, epilepsy and attentional concerns that will lead to clinical visits and assessment (Gillberg & Fernell, 2014). For this reason, the phrase '*Autism-Plus'* has been coined to encapsulate the comorbidities tied into many ASD clinical profiles, and to highlight the need for holistic treatment (Gillberg, 2015).

Further Communication Disorders are also outlined in the DSM-5 (APA, 2013). These include processing language (Language Disorder), phonological and articulation difficulties (Speech Sound Disorder), stuttering (Childhood-Onset Fluency Disorder) and the pragmatic use of verbals and non-verbals (Social (Pragmatic) Communication Disorder) – the latter of which serves as an alternate diagnosis to ASD when inflexibility is not present (APA, 2013). Language difficulties should not be understated, as they serve as a red flag for intervention. Communication difficulties and language delay are some of the earliest developmental difficulties to emerge (short of motor domains) (Anckarsäter et al., 2008; Sim et al., 2013) and serve as an indicator of later emotional and conduct concerns (Sim et al., 2013). Of the children who screen positive for a Communication Disorder at age 2.5, 60% had an established NDD at age 7 when assessed by the researchers (Miniscalco et al., 2007) and 40% had an established NDD at age 7 when national Swedish clinical registers were used to determine diagnoses (Miniscalco et al., 2018).

Indeed, the language module of the A-TAC serves as specifier for ASD, as well as serving as an 'Early Marker' in the factor structure of the A-TAC (Anckarsäter et al., 2008). Furthermore, 'Language' and 'Social Interaction' difficulties constitute two separate modules under the 'ASD' umbrella, with the addition of the 'Fixations' module.

The United States CDC currently places the prevalence of ASD at 1 in every 44 of school going children (CDC, 2022). ASD is similarly found in 1-2% of Swedish population samples (e.g., Besag, 2017; Gillberg, 2014; Larson et al., 2013, Selinus, 2015). ASD presents common overlap in the symptom domains of epilepsy, AD/HD, and sleep disorders (Besag et al., 2016; Besag, 2017), affect disorders, IDD, dysfunction in sensory integration, gender dysphoria and TD (Sharma et al., 2018). A high co-occurrence of ASD with AD/HD (and vice versa in up to an estimated half of all cases) and chromosomal conditions such as Down Syndrome or Fragile X Syndrome has been noted (Sharma et al., 2018). ASD is also found to overlap in a portion of pre-pubescent children with a rare form of early or childhood onset schizophrenia (Fitzgerald, 2014;

Sharma et al., 2018), although this constitutes a minute portion of a population. Nonetheless, much research has been conducted only considering the most severe cases of autism (Besag, 2017). Non-impairing variants of ASD in children that do not attend clinics will continue to be difficult to track without active screening.

An additional issue in ASD is how vastly underdiagnosed girls are compared to boys, at a male-to-female ratio of 4:1 to 3:1 (Loomes et al., 2017). This is owing to that fact that the current DSM criteria are based off a particular phenotype (sometimes dubbed the 'male' phenotype), and as a result, girls are more likely to go undiagnosed and untreated, or be diagnosed with non-neurodevelopmental, psychosocial, and psychiatric concerns such as affective disorders, personality disorder and schizophrenia (Kirkovski et al., 2013). Those girls who do diagnose with ASD thus commonly demonstrate the "clinically impairing variant" form of ASD (Gillberg, 2014, p. 36). In contrast, many girls with ASD have been noted to demonstrate better imaginative and imitative play, better linguistic skills and more socially focused fixations than boys, which may mask said girls from diagnosis (Kirkovski et al., 2013).

2.4.2.2. Attention-Deficit/Hyperactivity Disorder

AD/HD is persistent patterns of 1) inattention, and 2) odd activity levels or impulse control across two or more settings before age 12 (APA, 2013). Research suggests these two domains represent separate neuro-aetiological pathways with different sequelae of impairment (e.g., Beauchaine et al., 2010; Lambek, 2018; Van Hulst et al., 2015). Assessment is achieved through parental and child structured interviews, and investigation into context-variable behaviours of the child, such as at school (Plizka, 2015). The DSM-5 (APA, 2013) outlines:

- **Poor attention**. Individuals may struggle both in directing and sustaining attention (Gillberg, 2014). They make unnecessary mistakes, fail to organise properly and display an avoidance of mentally taxing activities. Furthermore, individuals appear forgetful or fail to follow instructions. This is arguably more linked to slower perceptual and response timing, possibly indicative of lapses in attention (Van Hulst et al., 2015) and poor vigilance (de Zeeuw et al., 2012). This links to poor school performance (Singh et al., 2015).
- **Hyperactivity or impulsivity**. Individuals may appear inappropriately fidgety, talkative, and over-active compared to peers. With regards to impulsivity, the child may blurt out

answers, interrupt others, struggle to wait for their turn or delayed rewards, or may otherwise physically act without thinking. Although the profile of AD/HD includes varying degrees of emotional dysregulation, executive function deficits (including poor working memory), and apparent 'low stamina' or neural under-arousal (Cockcroft, 2011; Gillberg, 2014) – the hyperactive-impulsive domain appears particularly linked to negative reactivity and aggression (Plizka, 2015; Qian et al., 2016) and poor peer relations (Singh et al., 2015).

Specifiers include AD/HD predominantly inattentive (AD/HD-PI) (i.e., Attention Deficit Disorder (ADD)), AD/HD predominantly hyperactive-impulsive (AD/HD-PH/I) and combined presentation (ADHD-C) – the latter two of which arguably align to the ICD-10 classification for Hyperkinetic Disorder (APA, 2013; Gillberg, 2014). Indeed, research has tried to demonstrate different neural correlates, cognitive models, and trait-factor models for inattentive and hyperactive-impulsive phenotypes. This has led to proposition of a multi-pathway, heterogenous understanding of AD/HD as a condition (e.g., de Zeeuw et al., 2012; Singh et al., 2015).

The fronto-striatal neural system is implicated through abnormal composition, poor connectivity, or lower dopaminergic activity (Beauchaine et al., 2010; Lambek et al., 2018; Singh et al., 2015). In this dual-pathway model, poor functioning in dorsal regions may relate to 'top' down executive functioning and poor inhibitory control (Lambek et al., 2018; Singh et al., 2015). Poor functioning in ventral regions (i.e., the 'reward circuit') may relate to a 'bottom-up' impact on planning that results in an aversion to delay (Lambek et al., 2018; Singh et al., 2015). Lower neural-connectivity and dopamine activation results in a higher threshold that must be passed for rewards to be 'registered' (Beauchaine et al., 2010). Cognitive models have also been posited for AD/HD subtypes with regards to the principle impairing trait. One factor group to emerge in cognitive performance is the 'slow reactivity' group implicating impairment to response timing and attention; whilst a second group to emerge are those with poor (cognitive) self-control (de Zeeuw et al., 2012; Van Hulst et al., 2015).

Controversially, inattentiveness appears more common than hyperactivity, and additional common difficulties such as DCD and perceptual and learning struggles are often not addressed (Gillberg, 2014). Thus, a Nordic term used is 'Deficits in Attention, Motor Control and Perception' (DAMP), often reflecting a combination of AD/HD-PI and DCD. Earlier

presentation of symptoms (particularly emotional dysregulations and hyperactivity-impulsivity) (Qian et al., 2016) correlate to an increased risk for oppositional defiant disorder (ODD) in up to 60% of cases (Gillberg, 2015). From a dimensional perspective, it is argued that the trait of impulsivity leads to '*externalising disorders'* such as AD/HD-PH/I, ODD and CD, with common, heritable neural-substrates, and which are modulated by variables such as ecological factors (Beauchaine et al., 2010).

As with language, hyperactivity has been found to be an early 'red-flag' trait and as such the A-TAC 'Impulsivity and activity' module constitutes one of the screen's "Early Marker' factor domains (Anckarsäter et al., 2008). In the A-TAC, core AD/HD comprises the modules for 'Concentration and attention' and 'Impulsivity and activity'.

AD/HD appears to be one of the most prevalent NDDs in European studies, such as in Sweden, manifesting in up to 5-10% of children (e.g., Besag, 2017; Gillberg, 2014; Larson et al., 2013; Selinus, 2015). This is corroborated in SA, in a surprising presence of prevalence data, at around 5% of school-going children (Bakare, 2012). *Impairments* owing to AD/HD may persist into adulthood (Torrente et al., 2014), for around 60% of individuals, and double the number of boys than girls will be diagnosed (Singh et al., 2015). AD/HD is also excessively represented as an overlapping reverse-comorbidity to other NDDs (referring to cases where a condition is diagnosed as an addition to another, principal diagnosis) (Plizka, 2015). AD/HD profiles often result in poor academic performance, evident from the first year of school (Singh et al., 2015).

Around two thirds of children with AD/HD experience concomitant ODD (Gillberg, 2014), *of which* around a further 10-20% will progress to develop CD and, by adulthood, possibly antisocial personality disorder (Gillberg, 2014; Singh et al., 2015). This serves as a principal pathway towards substance use disorders (Beauchaine et al., 2010; Plizka, 2015). When taking the level of parent education into account, it particularly appears to have the greatest influence on antisocial behaviours and interpersonal functioning (Selinus et al., 2015).

2.4.2.3. (Specific) Learning Disorders

Constituting three separable domains, the DSM-5 describes LDs as struggles in acquiring and utilising keystone academic skills, despite normal cognitive and intellectual functioning (i.e., an intelligence quotient above 70), adequate schooling, language proficiency and an absence of sensory concerns (APA, 2013; Döhla & Heim, 2016; Petretto & Masala, 2017). The condition is

often formally picked up in Grade 1 (Petretto & Masala, 2017). Although optimum criteria are debated, clinicians are expected to evaluate the domain specific impairment of the child compared to their cognitive abilities demonstrated in psychometric measures of intelligence (Petretto & Masala, 2017). DSM-5 (APA, 2013) domains include:

- **Dyslexia**. This refers to deficits in reading ability, including whole-word recognition, lexical recall, and phonetic decoding (Landerl et al., 2009). It thus encompasses slow, laborious, and effortful reading, or struggling to understand the underlying meaning of text. Rather than an issue of perception, dyslexia is now believed to stem from cognitive struggles in processing, storing, and integrating input (Landerl et al., 2009; McLoughlin & Leather, 2013; Moll et al., 2016).
- **Dysgraphia**. This refers to deficits in writing ability, although it does not feature as heavily in research investigating the distinction between reading-deficit and arithmetic-deficit clinical profiles. This may partly be due to it appearing closer connected to dyslexia (Döhla & Heim, 2016). Criteria may include issues with spelling or issues with the motorically written expression. Furthermore, issues in automating writing skills are evident, leading to effortful control and a loss of attentional capacity as in AD/HD (Döhla & Heim, 2016).
- **Dyscalculia**. This refers to deficits in arithmetic and the "processing of symbolic and non-symbolic magnitudes" (Landerl et al., 2009, p. 309). Symptom criteria for the domain include struggles in practically calculating and working with number facts and numerosity, as well as in mathematical reasoning. The difficulties experienced by individuals with dyscalculia alone in number processing appear distinct from the phonological difficulties in individuals with dyslexia alone (Landerl et al., 2009).

Although contested, research suggests each LD represents a unique cognitive profile, with impairments being additive in nature (e.g., Landerl et al., 2009; Wilson et al., 2015). Some research has gone into whether a similar core deficit, such as poor attention, underlies LDs despite differences in the performance domain impacted. Attention issues and outright AD/HD are often comorbid with LDs (Moll et al., 2020), and cognitive components of attention such as processing speed and working memory may be significantly impacted across LDs (Moll et al., 2016). Nonetheless, findings suggest that even the separable components of attention are

differently aligned to each LD, with processing speed and phonological working memory more implicit in dyslexia, but not in dyscalculia (Landerl et al., 2009; Moll et al., 2020). A multi-deficit model and multi-factorial view of LDs is thus espoused (e.g., Döhla & Heim, 2016; Landerl et al., 2009; Moll et al., 2020). When considering comorbidity, LDs may go unnoticed when overshadowed by other comorbid NDD concerns (Gillberg, 2014).

Prevalence rates for LDs may vary widely in literature, ranging from 1.5% (Selinus et al., 2015), to 4-7% (Landerl et al., 2009), to the APA (2013) estimation of 5-15% of children. Such wide variation is likely owing to variable 'tests' of cognition or intelligence that are used, in general and with regards to each domain of LDs specifically (Landerl & Moll, 2010). When assessing separable domains, we can observe a preponderance of dyscalculia in girls (Landerl & Moll, 2010), whereas a preponderance of dyslexia is observed more in boys (Gillberg, 2014; Landerl & Moll, 2010). Dyslexia demonstrates a 20-50% comorbidity with attentional and behavioural disorders such as AD/HD and CD, and 9-29% with affective disorders (Moll et al., 2020). LD domains demonstrate common overlap with one another (Landerl & Moll, 2010), and may persist into adulthood (Wilson et al., 2015).

2.4.2.4. Neuromotor Disorders

In the DSM-5 (APA, 2013), neuromotor disorders include DCD, Stereotypic Movement Disorder, and several categories of TDs.

DCD (dyspraxia) is age-inappropriate struggles in the development (skills learning) and execution of motor performance to a degree that impairs daily functioning, and may present in poor posture, poor balance, discoordination, motor 'slowness' and clumsiness (APA, 2013; Farmer et al., 2016; Wilson, et al., 2017). Such deficits include fine and gross motor tasks. This is further demonstrated by poor mirroring, poor end-point task organisation (including a failure to predict the grip, angle, body rotation and manoeuvring that will lead to a comfortable end-point state) and poor motor regulation/inhibition when cognitively overloaded (Adams et al., 2016; Wilson et al., 2017). DCD is a common NDD comorbidity but is often missed due to overshadowing by a 'primary diagnosis' such as ASD (Gillberg, 2014).

Although motor achievement may be inefficient compared to age peers, these children are still capable of developing motor skills if targeted intervention through explicit coaching is pursued, so that task performance is *over*-learned to the point of being easily retrieved (Biotteau

et al., 2016). With regards to intervention needs, three ‘subtypes’ have been delineated. Type 1 demonstrates slowness and clumsiness without language production difficulties, which appears to be most common and requires skills coaching and environmental adaptations. Type 2 includes slowness in the absence of clumsiness or verbal concerns, and thus would only require time concessions. Type 3 includes verbal and orofacial dyspraxia (meaning that the actual machinations for word formation are impacted and result in mumbled, mixed or slow speech), and this results in a noted increase in verbal and peer struggles and anger outbursts (Farmer et al., 2016). The criteria of the DSM-5 arguably focus more on the Types 1 and 2.

Motor dysfunction is not uniform across tasks, and simple tasks may be more rapidly learnt (Wilson et al., 2017). The more complex the task, the more the child will struggle with sequencing and adapting known skills to the new task without help (Wilson et al., 2017). They will often rely on visually trying to control their performance, owing to innately poorer proprioception (Farmer et al., 2016). Children with DCD tend to demonstrate poorer school performance on average than peers (Harrowell et al., 2018). Children may also self-consciously recognise the inefficient pace at which they acquire skills, and in shame may choose to withdraw from, or reduce, a variety of motor activities – which may result sedentary behaviour and reduce needed opportunities for motor development (Milander et al., 2014; Wilson et al., 2017).

Additional neuromotor conditions include Stereotypic Movement Disorder and TDs. The former encapsulates repetitive, sustained and seemingly purposeless motor actions that hamper functioning and may or may not lead to self-injurious behaviour (APA, 2013). The A-TAC does not have any items necessarily directed to this issue. The tics that comprise TDs, on the other hand, are sudden, repetitive bodily and vocal actions that are partially in the individual’s control when consciously recognised but are performed to temporarily relieve some sense of tension (Efron & Dale, 2018; Yang et al., 2020). Although 1/4 of children may demonstrate a ‘phase’ of performing tics, TDs are chronic – although as a pattern do significantly improve into adulthood, with an otherwise waxing and waning pattern in the individual’s daily life (Efron & Dale, 2018).

Intervention for TDs includes antipsychotic medication and behavioural modification (Yang et al., 2020). Tourette’s Syndrome is an example of a TD where motor and vocal tics are both present (Efron & Dale, 2018). It is estimated that at least 50% of individuals with a TD experience AD/HD, and a resultant increase in disruptive, non-compliant behaviour, schooling

difficulties, and additional LDs (Murphy et al., 2013). Existing literature concurs high rates of overlap with AD/HD, obsessive-compulsive disorder (OCD) and impacted affect (Efron & Dale, 2018; Yang et al., 2020), as well as negative fall-out that includes bullying (Yang et al., 2020).

I have already discussed how language and hyperactivity serve as early warning signs, and these are preceded only by motor abnormalities (Anckarsäter et al., 2008), which may be expected to have raised concerns by age 2 years already, as has been found in a sample of Japanese infants (Hatakenaka et al., 2016b). The A-TAC 'Motor control' module thus represents another element of the 'Early Marker' factor structure (Anckarsäter et al., 2008).

DCD prevalence estimates range around from 4.5% in Swedish samples (Anckarsäter et al., 2008) to 5-6% (Farmer et al., 2016; Harrowell et al., 2018; Selinus et al., 2015). In two SA studies of Grade 1 learners, prevalence rates were found for moderate (8%) and severe (7%) DCD (Milander et al., 2014), and for severe DCD in 6% of the sample with marked learning-related impacts (Milander et al., 2016b). This suggests higher rates in SA than is seen in international literature (Milander et al., 2014). The DCD ratio of SA boys to girls was 1.6:1, supporting international literature on greater male presentation (Milander et al., 2014). DCD demonstrates high overlap with AD/HD, as shown by attention difficulties in 88% of children with DCD (Farmer et al., 2016). This is also in line with Gillberg's (2014) discussion of the core domains of DAMP as an overlap of AD/HD and DCD in 50% of formally diagnosed DCD cases. Despite the connection between AD/HD and conduct concerns, ODD or CD are particularly rare in cases of DAMP, while risk for ASD symptomology and learning concerns are higher (Gillberg, 2014). This implies the DAMP diagnosis is less aligned to the ADHD-PH/I phenotype.

2.5. THE NEED FOR EFFECTIVE SCREENING

An effective screen is one that has been adapted for appropriate use in the setting that it is best suited for (Clemens, 2002). As discussed, few studies have adapted multi-domain NDD screens for SA use. The developing brains of children, although at their highest degree of plasticity, are exceptionally sensitive to environmental input (WHO, 2018). Thus, efficacious childhood screens are vital to enable early access of intervention. In addition to the neuroplasticity of children, early intervention decreases overall cost of treatment across the lifespan (RSA DoSD, 2015; WHO; 2018).

The impact of late or no intervention has noteworthy functional and developmental implications for children with NDDs. Such consequences include high levels of manifest comorbidities, global developmental delay (including language and cognition), conduct issues and possible progressive attacks of epilepsy, which may remain or develop if left unaddressed (Carlsson et al., 2013). Unaddressed NDD infliction may progress into adulthood disorders such as substance abuse, affective disorder (Plenty et al., 2013), and antisocial conduct (Beauchaine, 2010) due to repeated experiences of social rejection (Singh et al., 2015). Or the individual may develop dysfunctional beliefs and cognitions that perpetuate struggles, increase affective difficulties, and reinforce functional impairment (Torrente et al., 2014).

Already by adolescence, the secondary consequences of unaddressed NDDs can be seen in mood concerns, conduct, chronic fatigue, and chronic pain, amongst others (Gillberg, 2014). For example, children with DCD, and comorbid AD/HD, present with peer difficulties and social isolation, low sense of self-esteem that leads to withdrawal, poor school performance (which may impact on opportunity outcomes), anxiety and depression (Farmer et al., 2016, Gillberg, 2014; Harrowell et al., 2018). Impacted early development may result in less social skills development and lower academic success (Richter et al., 2019). Multiple, untreated, comorbid, impairing domains may explain the poor trajectory of such children across contexts. Moreover, an increase in the severity of NDDs such as AD/HD may demonstrate a concomitant increase in parental stress, and, with behavioural issues, broader family dysfunction (Theule et al., 2012).

2.6. DIFFICULTIES IN SA TRANSLATION WORK

As I aim to pursue translation and adaptation of the A-TAC screen into isiXhosa and Afrikaans, it is important to understand the dynamics of translation work in SA. The goal of translation procedures is to ensure correctly interpreted content and functional utility of the measure, but also to counter any data contamination in research stemming from the translated measure (de Wet et al., 2020). A standard working model endorsed for cross-cultural document translation is to translate said document from the original source language [L1] to the second target language [L2]. Following this, an independent translator converts the L2 document into a new, back-translated version of L1 [L1*]. L1 and L1* are then compared for any discrepancies (Brislin, 1970). The ‘committee approach’ is also used in this study, in which the translation team works as a unit to scrutinize translations (Brislin, 1970).

A drawback of translated documents (including tertiary-institute translated ones) is they tend towards over-formality, convolution, over-literalness, and a source language grammar focus, which does not meet the functional needs or colloquially understood terms of the target language (e.g., Bozalek, 2013; Colina et al., 2017; Dawson-Squibb & de Vries, 2020; de Wet et al., 2020; Guler et al., 2018). Thus, even translations can be a service-access barrier in SA. Ineffective translation can be frustrating to the reader, and ambiguity is seen in that, even though isiXhosa speakers may desire translated materials, they predominantly opt for English materials presented to them (Dawson-Squibb & de Vries, 2020; Guler et al., 2018). They express that they cannot follow the "high" translation register used (Dawson-Squibb & de Vries, 2020, p. 2279).

In SA, one reason may be the distinction between rural and urban dialects when deciding on a 'standard' to use (de Wet et al., 2020). Urban language groups mix, and different linguistic repertoires merge to form complex networks of code switching and translanguaging (Dowling & Krause, 2019; Makalela, 2014). Such blends of repertoires come to be known as '*kasi-taal'* (Makalela, 2014). It should be noted that owing to the phenomenon of kasi-taal, any 'purist' attempt at translation is open to critique. However, for the purposes of this study, code-switching or translanguaging is not pursued, as the repertoires involved in such translanguaging would be too variable between communities.

There could be concerns for assessing psychiatric conditions on the assumption that cross-cultural manifestations will look the same. This study would not assure *construct* validity (Foxcroft & Roodt, 2013) or *cultural equivalence*, wherein the expression of a difficulty (e.g., a mood disorder) is considered as relevant and performed in the same way between cultures (Colina et al., 2017; Jones et al., 2001). Yet, NDDs are neurologically based and thus less influenced by social context. For an example, an SA study on AD/HD across language groups found remarkable similarities in symptom manifestation (Meyer et al., 2004). The A-TAC also serves as a proxy to DSM-5 criteria. It is beyond the scope of this study to challenge cross-cultural applications of the DSM-5 criteria.

2.7. THE A-TAC

2.7.1. An Introduction to the A-TAC

The A-TAC is an open access tool aligned almost verbatim with symptom domains for DSM-IV NDDs (Larson et al., 2010). Yet, it is still built on the logic of ESSENCE, allowing one

to view domain overlap, and is further presented in modules that do not guide participants towards predicting and selecting particular conditions, thus not creating bias (Lundström et al., 2015). Each NDD or related disorder has their own module (with a total of 20 modules), except ADHD (2) and ASD (3). Modules comprise gate questions which are scored towards screening, follow-up questions for supplementary insight, and an indicator of severity and current presence.

Domains assessed by the A-TAC by way of one or more modules are: Motor Control (DCD), Perception, ADHD, LDs, Planning and Organising, Memory, ASD, Tics, Compulsions (OCD), Eating Habits, Separations (attachment concerns), ODD, Anxiety, Mood, Concept of Reality (Psychosis) and Miscellany. When speaking broadly of a category such as eating, the A-TAC reflects an umbrella of possible concerns such as PICA, rumination disorder, avoidant/restrictive food-intake disorder, anorexia nervosa, bulimia nervosa or another specified feeding or eating disorder (APA, 2013). The same stands true for mood, anxiety, TD and attachment disorders included. Items are scored on a 3-point Likert Scale, ranging between "Yes" (1), "Yes to some extent (0.5) and "No" (0) (Hansson et al., 2005). Originally developed to be convenient for telephonic administration (Hansson et al., 2005), the screen is intended for parents or guardians of a child to complete. Items can be endorsed if the child has at any stage of life demonstrated concerns compared to their peers.

2.7.2. Previous Validation of the A-TAC

The A-TAC and its sub-domains have been validated in several studies to date (as listed below). In an initial clinical study of 84 Swedish participants and 27 controls (7–18-year-olds), good-excellent validity coefficient scores were found for the predictive validity of core conditions: ASD (Area Under the Curve (AUC) 0.88), AD/HD (AUC 0.90), TD (AUC 0.84), LD (AUC 0.74) and DCD (AUC 0.71) (Hansson et al., 2005). The study also showed good initial inter-rate reliability (Kappa 0.60). The several studies listed below, comprising large samples (9- and 12-year-olds) drawn jointly from the Child and Adolescent Twin Study in Sweden and Swedish National Patient Registry, have maintained good-excellent validity scores, especially regarding the strength of ASD and AD/HD modules as follows:

- Halleröd et al. (2010) found moderate convergent validity with the Child Behaviour Checklist (correlation coefficients 0.30 – 0.55) for core NDDs, in which it was concluded that the A-TAC demonstrates greater utility towards definitive diagnoses.

- Larson et al. (2010) found module gate questions worked as well as sum scores, aiding the viability of a short A-TAC version; as well as found that IDD did not significantly bias scores. Sensitivity and specificity coefficient for each module, respectively, were: ASD (0.91/0.80), AD/HD (0.91/0.73), DCD (0.63/0.68), Perception (0.92/0.46), Learning (0.92/0.60), Planning & Organizing (0.82/0.70), and TD (0.88/0.86).
- Larson et al. (2013) found predictor values of: ASD (AUC 0.91), AD/HD (AUC 0.77), LD (AUC 0.80), and TD (AUC 0.79). The measure's ability to distinguish general presence or absence or NDDs, but not specific diagnoses, was explained by the studies three-year gap between screening and clinical assessment.
- Larson et al. (2014), with regards to inter-rater reliability, demonstrated moderate Kappa values (although the ASD module reached a perfect score of 1.0).
- Anckarsäter et al. (2011), generated good internal consistency scores for ASD ($\alpha = 0.86$) and AD/HD ($\alpha = 0.92$), as well as a moderate score for CD ($\alpha = 0.61$). Good internal consistency was found for all modules with more than four gate questions.
- Selinus (2015) found predictor values for ASD (AUC 0.77) and AD/HD (AUC 0.91).
- Mårland et al. (2017) calculated good-excellent predictor values for: ASD (AUC 0.89), AD/HD (AUC 0.86), LD (AUC 0.89), TD (AUC 0.83), and CD (AUC 0.85); and fair-moderate predictor values for: ODD (AUC 0.77), DCD (AUC 0.77), OCD (AUC 0.68), and ED (AUC 0.56). Scores showed variation based on the age of the child.

Development of the A-TAC was geared towards epidemiological studies but has steadily gained use in clinical research due to the insight it produces surrounding core, comorbid, and subthreshold traits (Larson et al., 2013; Larson et al., 2014). The factor structure across the various modules of the A-TAC comprises a triad of three factors: 1) externalising conditions, 2) early markers (e.g., language, motor control and hyperactivity) and learning concerns, and 3) compulsions and fixations (Anckarsäter et al., 2008).

The modules have been translated into and used in French and Spanish research, including a Spanish validation study of the ASD modules (net AUC 0.96, $\alpha = 0.93$) (Cubo et al., 2011). No validation studies have yet taken place in SA, although the measure may be used for developing clinical insight. Age acts a moderating variable for the A-TAC (Mårland et al., 2017). Although the A-TAC may be reasonably utilized across childhood, certain domains such as

learning (i.e., in a structured classroom setting) are difficult to apply when the child is too young. Furthermore, modules such as 'eating' centre pointedly on adolescent concerns (e.g., purging).

It must finally be noted that the A-TAC screen contains verbatim the AD/HD (inattention and activity/impulsivity levels) and ODD items of the SNAP-IV 26-Item AD/HD Rating Scale developed by Swanson et al., (1981), which was updated as per DSM-IV revisions (Swanson et al., 2012). The SNAP-IV has gained popularity as an educator- and parent-answered AD/HD screen, and effective translations into isiXhosa (for which no existing such translation could be found) would benefit both the A-TAC and SNAP-IV screen. Nonetheless, the two measures differ in scoring protocol, using a three- and four-point Liker scale, respectively. For this reason, psychometric properties may differ. It must be cautioned that although the SNAP has gained popularity, it demonstrates inconsistent psychometric performance and must only be treated as a screener for clinical insight, and not as a formal diagnostic tool (Hall et al., 2019).

2.8. CHAPTER SUMMARY

The literature reveals a dearth of multi-condition NDD screens and co-morbidity rates in SA. The additive burden of NDD co-morbidities may have significant functional, social, and academic consequences for the life-trajectories of individuals if left unaddressed. The A-TAC, which has repeatedly proven to be an effective, valid screen for NDDs in Sweden, may help fill the current niche in SA towards clinician insight. The current study takes place with a participant group of isiXhosa-speaking parents, and as such Xhosa medical pluralism and mental health awareness in peri-urban communities has been discussed. It is important to recognize how cultural variations in linguistic concepts, mental health literacy and healthcare support seeking behaviours would shape screening practice and receptivity.

Chapter 3, to follow, will discuss the various conceptual frameworks relevant to my study. This includes the diagnostic framework used in conceptualising NDDs, the developmental pathways through which NDD presentations can be understood, and finally the social constructionist analytical framework that will be used in the assessment of study data.

3. GUIDING THEORETICAL FRAMEWORKS

3.1. INTRODUCTION

This study is multifaceted in its focus, and thus several streams of theory are used to underpin it. This includes 1) the diagnostic underpinning of the A-TAC, 2) the aetiological underpinning of NDDs and closely comorbid conditions (with a particular emphasis on the gene-environment interaction model currently favoured), and 3) the social constructionist paradigm that will lead study focus group engagement and thematic analysis. It should be noted that, although screen translation procedures and thematic analysis of data also constitutes approach frameworks, these are methodological in nature and so will be discussed in the following chapter on methodology.

3.2. THE DIAGNOSTIC FRAMEWORK

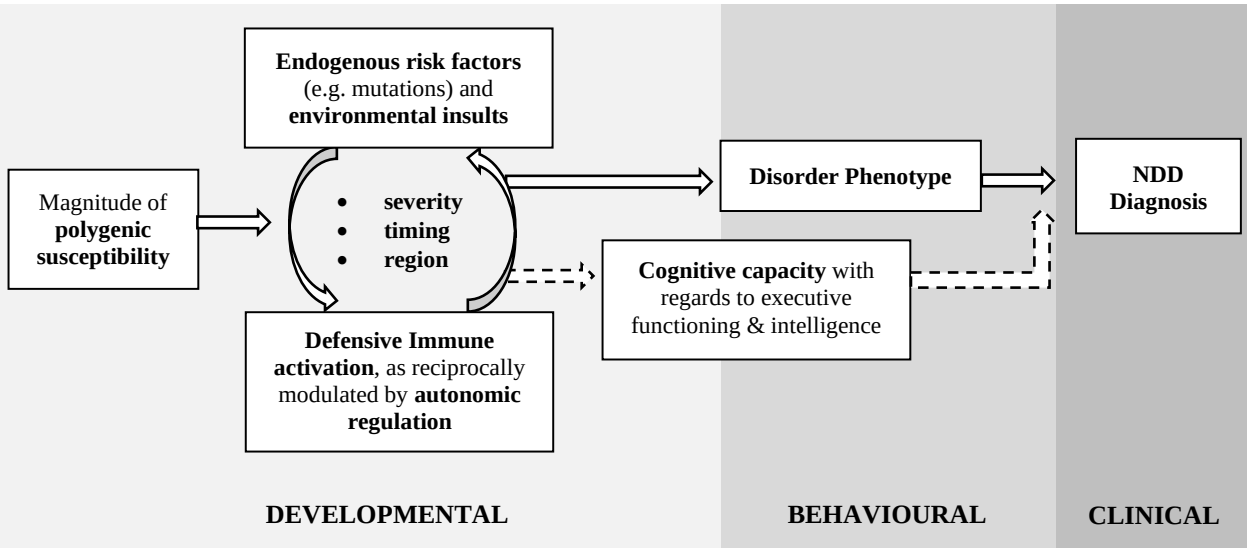
The A-TAC was developed in accordance with the DSM-IV. Although the DSM-IV was held to follow an a-theoretical construction of psychosocial disabilities, the DSM-5 has shifted to conceptualising disorders per their presumed aetiology (Cooper, 2018). Although subtle changes exist between the two versions in terms of subtypes, specifiers, classifications and cut-off criteria, the core conception of NDDs has remained relatively stable. The largest shift was merging Autistic Disorder, Rett's Disorder, Asperger's Syndrome, Childhood Disintegrative Disorder and PDD – NOS into the diagnosis of ASD (APA, 2013). Nonetheless, the A-TAC has been revised to mirror this combined inquiry since its initial validation (Hansson et al., 2005).

3.3. CONCEPTUAL NDD FRAMEWORK

As discussed, ESSENCE reiterates that no individual can be fully reduced to a categorical abstraction, and that a broader scope must always be pursued where possible (Gillberg, 2010). For child development, a transactional model is required. Notably, this implicates the gene-environment interaction (Yang & Khoury, 1997). Gene susceptibility, as with NDDs (APA, 2013; Licari et al., 2019, Sarovic, 2019), interacts with ACEs that compound or mitigate disease expression (Yang & Khoury, 1997). The number and severity of symptoms, and overlapping symptom domains, may extend from ACEs (such as are experienced across SA) (RSA DoSD, 2015). Such ACEs cause epigenetic alteration to gene manifestations and thus neural tissue differentiation, which impacts the 'base' from which adaptive development must build (RSA DoSD, 2015; WHO, 2018). This stance is consistent with current NDD conceptualisations. To operationalise the above dynamic, Sarovic (2019) posited a three-component model:

Figure 1

The Underpinnings of NDD Development and Detection



Note. Adapted from "A framework for neurodevelopmental disorders: Operationalization of a pathogenetic triad for clinical and research use", by D. Sarovic, 2019, p. 3.

In Sarovic's (2019) framework above, 1) the biological-developmental stage sees the inheritance of polygenic susceptibility to disease onset. Susceptibility reciprocally interacts with endogenous, intra-uterine and mechanical risks, and (auto)immune activation (including the damaging possibility of neuro-inflammation). 2) Such ACEs impact on the form of neuro-tissue differentiation that occurs, which determines the phenotypic display in the behavioural stage and diverts resources from 'growth' to 'defence and repair', instead. 3) The child's capacity for cognitive compensations (if intelligence and executive functioning is left unscathed) may aid in the modulation or hiding of some symptoms and adaptation to environmental demands. Such phenomena have been noted in ASD (Livingston et al., 2020). The final phenotype may lead to (neuro-)psychotherapeutic visits, which will determine the diagnoses assigned in the clinical stage.

Thus, difficulties start in the nervous system and create sequelae of impairment. Presumed 'shared' networks or damage between NDDs reflect shared spectra of causes, traits and impacted capacities (Landerl & Moll, 2010; Licari et al., 2019). Such capacities include processing speed, working memory (Beauchaine et al., 2010; Moll et al., 2016), top-down and bottom-up attentional capacity (Singh et al., 2015), self-inhibition and emotional regulation as an

offset to externalizing (Beauchaine et al., 2010), sensory processing (Randell et al., 2019), abstraction and perspective-taking (Happé, 2015), and a host of additional processes. These 'spectra' intermingle and result in recognized NDD 'syndromes' and additional concerns such as affective disturbance, conduct difficulties, eating disorders, OCD and other issues. These additional categories ones in which NDDs are comorbid to a greater degree than would be expected by chance (Anckarsäter et al., 2008). The above outlines a multi-factorial approach to understanding NDDs (Licari et al., 2019).

3.4. THE SOCIAL CONSTRUCTIONIST PARADIGM FOR ANALYSIS

This ontology holds that data from participants only ever reflects an interpreted, mutually constructed version of reality (Terry et al., 2017). Social constructionism is concerned with perceptions and the subjective, habituated role of culture and societal influences (Galbin, 2014; Sagvaag & da Silva, 2021). Such influences impact individuals through the agreed (yet transient) meaning that social actors place on them (Sagvaag & da Silva, 2021). Thus, meaning is continuously enacted, shaped, and revised through the interactions of social actors, including the researcher (Bryman, 2016; Galbin, 2014). John Searle (1995) describes the different facets of subjectivity as including purely mental 'facts' (such as emotional experiences), social 'facts' (such as cultural dictates), and institutional 'facts' that impact whole bodies of groups or society in its entirety (such as language, finance, religion, etc) (as cited in Sagvaag & da Silva, 2021, p. 4).

I opt for a moderated, 'critical' constructionist approach. This indicates a position that a) participant testimony can never be taken to reflect (as an objective mirror) an image of any uniform social structure. However, concurrently, b) social structures have momentum independent of any single social actor. Social phenomena exist both as a subjective and objective reality (Galbin, 2014). Social structures such as language, although constructed and changed by the social actors within them, also exist outside of any given individual, and represent a 'pre-existent' construct individuals are enculturated into (Sagvaag & da Silva, 2021). As such, it is possible for participants to provide testimony to their experience of the social forces that exist independent of (whilst shaping) their individual personhood. The goal is not to produce an absolute truth, but rather a plausible *possibility* – a provisional claim – of what is happening in a

context and how it may be *transferable* (rather than generalisable) to other contexts (Galbin, 2014; Turnbull, 2002).

The constructionism in qualitative research is noted for employing a deductive, top-down theoretical integration of existing literature with emergent data (Terry et al., 2017). This requires analysis of the *researcher interpreted* latent content of data, supported by existing theory (Terry et al., 2017). It is thus vital that I provide a clear account of what is drawn from literature, what my preconception were, and what was gathered direct from participants - as this allows readers to be aware of the exact sequence of analysis (Sagvaag & da Silva, 2021).

3.5. CHAPTER SUMMARY

Though NDD diagnostic criteria have shifted across DSM editions, their core conceptions have remained stable. NDDs are viewed as an interplay of environmental and genetic factors/affronts that impact on neural development. It is most helpful to consider NDDs as a mixture of shared dimensions of impairment and varying capacities across individuals. For analysis, I opt for the critical social constructionism. This recognizes that although all participant (and my own) input is subjectively shaded by context, it is possible to point to ‘experiences’ of grander social phenomena that reflect a plausible interpretation of the social world.

Chapter 4, to follow, will address the approach of this study in seeking out participants, piloting and undertaking data collection, data management strategies, ethical considerations and the manner in which data analysis is undertaken.

4. METHODS

4.1. INTRODUCTION

I seek to engage with concerns around the accessibility of NDD screening in the Western Cape, SA. This necessitates balancing 1) provision of an adequately translated (Afrikaans and isiXhosa) screen and investigation of parental perceptions, with 2) time and resource limitations, and the broader COVID-19 climate. Research methodology should represent an appropriate pathway towards answering the research question through effective data collection and analysis (Bryman, 2016). To this end, I embrace and expand on certain established methodology, while certain novel approaches are utilised where a precedent methodology cannot not be found. In this chapter, I will provide a detailed breakdown of the participant recruitment strategies, data collection and screen adaptation approaches, data analysis steps and personal reflections.

4.2. RESEARCH DESIGN

Both Afrikaans and isiXhosa translation work included first-language speaker consultation, while isiXhosa focused aspects of the study additionally included a cross sectional groupwork design (please see Section 4.2.1). Groups assist exploration of how social norms and perspectives are co-negotiated by participants, with the allowance of interplay between members (Kristiansen & Grønkjær, 2018; Mack et al., 2011). Groupwork thus lends itself seamlessly to social constructionistic-oriented research. Rather than reiterating ‘objective truths’, group members bring with them diverse yet partially (thematically) overlapped experiences, and in the course of their interactions construct an agreed, and yet fluid, understanding of the discussion topic (Kristiansen & Grønkjær, 2018). The fluidity of such conclusions means they are only ever emergent, providing a glimpse at the underlying social influences at work, and contributing to grander discussions regarding such social influences (Rubel & Okech, 2017).

In two meeting sessions, a group of first-language isiXhosa parents worked with me to rank and adapt the A-TAC and discuss contextual understandings of child development and healthcare screening and provision more broadly. In both meeting sessions, the group engaged in the A-TAC adaptation, wherein a ‘mixed methods’ approach was included. In this regard, although personal insights into language use and meaning-making is inherently qualitative in nature, I used quantitative scales to confirm agreement across participants for each A-TAC item. This novel scale was used to ensure suggestions for language adaptation were not simply

idiosyncratic, but congruently supported by all group members. This allowed both flexibility in language alteration as well as consistency in confirmation checks (see Appendix R).

For a portion of the first meeting session only, group members engaged in a one-hour, semi-structured focus-group interview. This was to understand parental perceptions of child development and support. Within the constructionist paradigm, it is important to reflect on the fact that I as researcher am a part of the data construction through a) impacting participant response, b) spearheading particular themes in discussion and c) in acting as the final interpreter of the data (Birt et al., 2016; Sagvaag & da Silva, 2021). Bias cannot be completely removed from the process of analysis, but it may be mitigated or confessed. A benefit of groupwork is it partially counters bias. Rather than having myself sit with independent interviews and impose how they 'speak to one another', group members in their live interactions define what normative framework is reached (Kristiansen & Grønkjær, 2018).

4.2.1. COVID-19 Motivated Study Truncation

My intention was to gather both an Afrikaans and an isiXhosa group of participants. Unfortunately, participant seeking only commenced following Stellenbosch University Research Ethics Committee: Social Behavioural and Education Research (REC:SBE) approval on 1 July 2021, during the SA 'third wave' in COVID-19 cases [adjusted Alert Level 4, 28 June to 25 July 2021, with a sustained Western Cape peak running into August]. The educator contact that was to assist with Afrikaans participant recruitment in Groot Drakenstein indicated that the community was especially impacted by the COVID-19 third wave, with one prospective participant passing away before the educator could engage with them, and the educator themselves experiencing a family loss at the start of August. With sensitivity to the educator's lack of capacity to support this study, I decided to reduce the groupwork to the isiXhosa group. Thus, both isiXhosa and Afrikaans translations underwent the same initial processes, including consultation with my first-language speaking colleagues. However, from this point further, any groupwork, interview or participant descriptions relate only to isiXhosa-speaking participants.

4.2.2. Data Framework

To briefly reiterate, the purpose of the groupwork is to engage isiXhosa first language-speaking parents to 1) pursue a mixed-methods workgroup to comment on, modify and mutually construct adequate screen items for the A-TAC towards NDD screening, and 2) to pursue a focus

group to elaborate themes of NDD detection and child development. This was in order to broach the theme of SA NDD screening accessibility from a *supply* (i.e., existing adapted screen) as well as recipient *demand* (i.e., perceptions of and receptivity to healthcare forms, mental health detection and child neurodevelopmental themes) side.

The rationale in this dual-pronged approach is that adapted screens may not serve their function sufficiently if local context, tool application difficulties and recipient buy-in are not considered and explored. This creates multiple directions and facets to investigate. To ensure purpose-appropriate analysis and synchronisation of data, the below study aims framework was developed. This helps ensure that different points of data collected between 1) the A-TAC adaptation workgroup and 2) the qualitative focus group discussion, can be integrated towards the overarching study objective, and read with relevance to one another.

It is not uncommon to have a framework guide the structuring of analysis. An SA study by Schierenbeck et al. (2013) on mental healthcare access used the United Nations AAAQ healthcare framework to structure the results of their assessment. The framework centred on the Availability, Accessibility, Acceptability and Quality domains of healthcare provision, which did not unduly bias results (Schierenbeck et al., 2013). Within each category, results still take on a unique character that may confirm or subvert elements of broader discussions and literature.

Table 1

Projected Study Aims Framework Matrix

’DEMAND’ CONCERNS (receptivity and accessibility)	‘SUPPLY’ CONCERNS (A-TAC translated screen)
- Experience of health detection - Receptivity to health forms - Is individual- or assisted-completion preferable?	- Suggested screen/detection protocol - Reception to the adjusted A-TAC
- Existing conceptions of NDDs - Who would be approached when concerns arise?	- Conceptually clear A-TAC items - Who would parents wish to receive such a form?

Note. The table's content has been drafted around qualitative interview questions, as per Appendix D. The outlined grid only served as a guide, and additional points of interest were welcomed as they arose within the qualitative group interviews and thematic analysis.

4.2.3. Collaborative Design: The MLS

Procedural planning and practical arrangements were supported by the MLS for data collection and school support. This included the need to structure initial perceptions of screen items into a Likert scale (discussed later) and what ideal wording around the Likert scale would be. The MLS Director and I entered a signed research collaboration agreement to this extent (Appendix N), and the Director has further signed a non-disclosure agreement for participant details (Appendix O). The MLS was compensated for its support services as per the budget spreadsheet in Appendix P. The roles of the MLS Director were as follows:

- The MLS served as an **operational assistant** to me. In this regard, she was not acting as a data collector. The Director helped ensure that processes for the study ran smoothly. This included: putting myself in contact with her associate community educators, making venue arrangements for classrooms and Wi-Fi internet use at the community primary school, and serving as a co-facilitator during the digital groupwork.
- To this end, the MLS also served as a **language partner**, as I am overall monolingually English with only a casual understanding of isiXhosa. The Director assisted in translating consent forms, flyers, and scale items for the A-TAC adaptation work. As co-facilitator, the Director served as a translator and language-bridge, which helped ensure participants were free to speak in isiXhosa. Finally, the MLS provided translated transcriptions of the recorded focus-group work, so I could comfortably analyse the data in English.

4.3. PARTICIPANTS

This section only discusses isiXhosa speaking, recruited participants.

4.3.1. Study Setting

Study participants were recruited from an isiXhosa township primary school. The A-TAC is geared towards parent respondents and so I considered the input of such parents to be crucial to the adaptation process. The examples of Khayelitsha and Kayamandi will be used as a demonstration of such peri-urban, isiXhosa-speaking communities. These contexts experienced rapid expansion without parallel growth in local infrastructure networks (Petzer, 2015;

Sustainability Institute, 2017). There is a mixture of formal serviced housing, informal yet serviced housing, and informal housing on wholly un-provisioned land without access to water, power and sanitation services (Havenaar et al., 2008), due to a municipal lack of funding to pursue bulk infrastructure projects (Sustainability Institute, 2017).

This resource disparity perpetuates apartheid demarcations of the rich and poor, and results in the continuation of historical injustices and ultimately a failure to supply neither basic needs nor capacity for sustainable development in which individuals are empowered in their own skills and vocational endeavours (Petzer, 2015; Sustainability Institute, 2017). It is in such a context that the prevalence of early ACEs, strongly associated with child NDD concerns, may proliferate. It is too for this reason that tools specifically designed to be appropriate for such a community context (such as outlined above) and its needs, must be developed.

4.3.2. Participant Description and Sampling

I recruited first-language isiXhosa-speaking parents. The MLS Director is a member of several educator associations. For access to prospective parent participants, the Director utilized this connection to request that the Principal and Vice Principal of the study community primary school inform parents of the research. These colleagues were asked to share the study flyer should parents indicate interest. The written letter to the heads of the community primary school and the parent recruitment flyers are attached in Appendices A & B, respectively. The school served no further role in recruitment than informing parents of my study and facilitating contact with myself. This constitutes non-probability purposive sampling, as a specific institution was selected to sample a category of participant (isiXhosa parents), split by gender (Bryman, 2016).

The rationale for recruiting participants from the study setting is that it is a predominantly isiXhosa community. As discussed in Chapter 2, historically under-resourced communities may experience a greater degree of undetected ACEs, and so is representative of the population most in need of focused attention and support for NDDs. Thus, members would be able to give a tentative reflection as to how accessible information, adequate healthcare forms, and healthcare services are in their given context. However, the group cannot be claimed to reflect all township healthcare contexts or language dialects across the Western Cape. Nonetheless, I believe the participants may reflect themes and struggles that speak to grander discourses surrounding healthcare, detection, and child development.

The participants comprised six adult isiXhosa-speaking parents, as per acceptable group size parameters outlined by Terry et al. (2017). Gender was evenly split with three females and three males, all between the ages of 24 and 39. The limitations that exist owing to the younger participant group is explored in Section 6.3, as five of the six participants were under 35. The split gender presentation was geared towards ensuring balanced input in group discussions, should any gender-differentiated opinions exist. One instance of snowball sampling did occur. One of the participating parents had to withdraw the day before data collection commenced. The individual suggested a friend of theirs who would be interested in participating in the study (Bryman, 2016), and so full recruitment protocol was followed with this candidate the evening prior to the session.

4.3.3. Recruitment Strategy

Recruitment of parents took place over SMS. The **inclusion criteria** were that: the participant should be parents, isiXhosa first-language speakers, literate to a Gr. 9 level, and residing in the study community. The **exclusion criteria** were: individuals under 18 years old or where isiXhosa is not their first language. In this regard, parents were asked, their age, the grade in which they left school, and if isiXhosa was their home language. All parents who contacted me matched these criteria. It is likely that, as the inclusion and exclusion criteria were provided to the Vice Principal of the school, specific parents were approached with these parameters in mind. Additionally, it was preferable that parents should not have background experience with NDDs (and thus no additional lexicon or especially skewed favour towards screening). To assess this, prospective participants were given the following question:

- *Does your child, any other family member, or a friend's child have any confirmed difficulties with their development, or neurodevelopment /OR/ have you ever taken your child to a healer or healthcare worker because you were worried about their development or behaviour? [Yes / No]*
- *Unaye umntwana okanye omnye umntu kusapho lwakho, okanye unomhlobo onomntwama oneengxaki zokukhula njengomntwana (ukukhula komntwana), oneengxaki ukubazeko lwengqondo /OKANYE/ Ukhe uye kwagqirha nomntwana wakho okanye kwabasebenzi bezempilo ukuba ukhatazekile malunga nokukhula komntwana wakho? [Ewe / Hayi]*

In presenting this question, I realised it was perhaps overly reductionist. From my own process notes, the term '*confirmed difficulties'* was vague, and does not necessary make clear that the question is centring on a defined diagnosis. Although, several participants indicated they were unsure, or that doctors had not provided a proper explanation of concerns whenever these have arisen. Several members, who were unsure, seemed to outline child development and NDDs in educational terms (i.e., homework difficulties, initial difficulties acclimatising to class, peer group concerns). However, none of the parents indicated awareness of a formal diagnosis or any prior focused training into neurodevelopment. Thus, after I had had extensive further discussion with the parents, I opted to include all members into the group.

On the day of the groupwork on 31 July, we brought participants printed versions of the consent form (see Appendix C). The MLS Director and I first went through the consent form with the participants and had them sign their consent to participation before any group processes began. For the second group day, 4 September (in which more screen adaptation work was done), the same consent form, less any sections on focus-group work, was presented over Zoom. Participants signed their consent privately to me on the Zoom chat-box feature. This was recorded and the digital consent has been securely stored.

4.3.4. Groupwork Arrangements

Given the COVID-19 pandemic, both in-person and digital group strategies were planned. The eventual group arrangement ended up being a hybridised version of these two routes. My preference was always for school-based groupwork. My intention was to arrange with the school to make use of a large, ventilated classroom or boardroom. If this were not possible, the alternative was to have participants join from home over Zoom with me pre-purchasing their data packages. Given the rise in COVID-19 infections around the first groupwork session, I decided that participants should not be gathered in the same room. However, there was concerns around signal connectivity and ambient noise for people working at home.

MLS arranged separate classrooms for each participant. This allowed for Wi-Fi access, quiet and social distancing. **31 July**: Five participants opted to work from the school using Zoom on their phones. One participant opted to work from home and was sent a 2GB data package at the start of the day. We provided participants a classroom, the school Wi-Fi details, printed consent and A-TAC forms, a pencil, an instant coffee sachet, and a plastic sealed container-

sandwich lunch. The participant working from home was brought the forms and lunch pack the morning of the group by the MLS Director. **4 September**: Five participants opted to work from the school using Zoom on their phone and one participant opted out of the study. Participants were provided sanitized instant coffee sachets and wrapped muffins.

The MLS Director and I worked from the school in the administrative offices via Zoom. The sequence of group activities for the session of 31 July ran as follows: We worked through the consent form. Participants were then given 45-minutes to read through the A-TAC and rank how clear items were. The group then discussed each item in turn. Each participants had a copy of the A-TAC, and a PowerPoint slideshow was also shared, listing single items per slide. The group then took lunch from 12:30 until 13:45. Following this, participants took part in a focus group discussion on their understanding of NDDs and child development, and their perspectives on healthcare detection and support for children. The session of 4 September focused on addressing the semantic meaning of screen items and adapting items that were unclear or incorrect in meaning. This ran from 9:00 until 13:30 with a 20-minute break in between.

4.4. PROCEDURES

4.4.1. Translation Adaptation Approaches

I sought to confirm the effectiveness in meaning relay in the isiXhosa and Afrikaans translated version of the A-TAC screen, to ensure **functional utility**.

4.4.1.1. Stages and Strategies in the Adaptation of the A-TAC

Stage 1. This concerned forward- and back-translation, and judgemental comparison of texts (Foxcroft & Roodt, 2013). Translations were completed for the full 11-page screen via the Stellenbosch University 1) Department of Afrikaans and Dutch (Afrikaans forward-translation), and 2) the Language Centre (isiXhosa forward- and back-translation conducted by two independent staff members) – towards research by the Neurodiversity Centre (NDC) (2022). The NDC provided explanations as to the purpose of each module and the peri-urban context in which it would be used. The MLS conducted the back-translation of the Afrikaans text. Following a source-language monolingual judgemental design (Foxcroft & Roodt, 2013), I compared the original English and back-translated English versions, and any inconsistencies were returned for correction.

Stage 2. Individual input was provided on updated screen items. For the Afrikaans version, the form was handed to an NDC first-language Clinical Psychologist to clarify the meaning/intention of certain items. Two colleagues from the Stellenbosch University Worcester Campus department of paediatrics assisted further. The A-TAC version was handed to the isiXhosa first-language team-member, who produced an independently translated version of the screen given qualms she had with the provided isiXhosa translation. Following on this, towards NDC, Breede Valley study preparations, I jointly met with the Afrikaans- and isiXhosa speaking colleagues, in order to work through core NDD modules of the A-TAC. This led to further adaptations or alternate suggestions of screen items. These different versions were deliberated either with the colleagues, or in the case of the isiXhosa screen, with the groups as well in Stage 3. The Afrikaans translation underwent final review with the MLS, but no groupwork.

Stage 3 involved the sample group of isiXhosa-speaking parents, towards further adaptation and confirmation of the translated A-TAC. Seeking the input of lay, first language speakers may correct the possibly overly formal and convoluted language register of the translated documents (de Wet et al., 2020). This essentially became a ‘committee’ design for jointly deliberating translated screen items. Variants of merging these two approaches have been used in previous literature, such as by de Wet et al. (2020) and the Colina et al. (2017) cited United States Oyendo Bien projects, which include Guillemen et al. (1993) and Herdman et al. (1997) (p. 276).

The committee approach is warranted by need for collaboration between field expertise, linguistic proficiency, etc (Colina et al., 2017). This was especially true because 1) of time constraint that prohibited the possibility of each participant producing an entire new translation version (especially given a lack of field expertise), and 2) the use of community-based participants ensured greater accessibility of the translation. Although community translators are critiqued for not being professionally trained, there are also proponents of utilizing participants is research who are also members of the community groups one wishes to reach (de Wet et al., 2020).

Additionally, the participants in the current study did not translate items from scratch, and simply assisted in adapting items. Thus, such assistance is beneficial provided discussion is mediated by an individual with greater topic expertise (i.e., myself) and with greater professional

language translation expertise (i.e., the MLS). The novel element is the screen rating scale that is used to check the understandability of items. This is an addition to existing suggested methodology, rather than a departure from it, and assisted me in structuring and tracking discussion with non-professional participant translators.

4.4.1.2. Translation Groupwork and Data Collection

The groupwork for adapting the translated A-TAC screen followed a guiding structure (see Appendix R), to ensure most core elements were addressed within the given time. It is common in translation work for unique strategies to be adapted with consideration for the study goals, context and resources (Colina et al., 2017). Firstly, the group checked the clarity and register of each A-TAC item, through use of a novel 5-point, translated Likert scale. Considering the limited amount of time available to run through an extensive screen, gate questions were prioritized as exampled in Appendix H. Items were assessed for all A-TAC modules.

For the *second* part of this process, I went through gate questions with participants, and noted their response according to the given Likert scale. Consensus at this stage constituted the majority scoring an item 5 and with no scores below 4. For the *third* part of this process, any item that was cause for confusion or unintended interpretation was re-broached per discussion between the group members, in order to seek alternatives. The second and third part of the process were carried over into the second group session on 4 September. In this stage, preference was given to correcting core NDD focused gate questions related to: DCD, ADHD, LDs, ASD, Tics and ODD. There needed to be consensus reached on an item. If the item was deemed understandable, with suggestions being more idiosyncratic, then the item was left as is. Finally, the group deliberated A-TAC was presented to my isiXhosa colleague and the MLS Director in turn, to discuss any final corrections and interpretations of the screen items. The full procedural layout for these steps is provided in Appendix R.

4.4.2. Focus Group Procedures

Following on translation groupwork surrounding the A-TAC screen on 31 July, participants took part in a semi-structured focus group discussion regarding NDD screen and translation accessibility, and healthcare support for child development. The optimal number of discussion group participants (towards bolstering multiple points of input) had to be balanced with resources, COVID-19 safety constraints and primary school venue allowances. To this end,

six participants were included in the group, which has been recommended as an acceptable number for group-based interviews by Terry et al. (2017). Including myself and the MLS Director, eight individuals were involved in the focus group. The benefit of focus groups is that they can provide a large amount of input in a relatively short timeframe (Mack et al., 2011). The focus group ran for one hour, which falls within the expected range (Mack et al., 2011).

4.4.2.1. Recording

Focus group recording was done from Zoom, which conforms to GDPR data protection protocols (Zoom, 2021). The benefit was that, in addition to promoting social distancing, 1) a group discussion, 'face-to-face' over video was still possible to facilitate, and 2) rather than needing multiple recording devices, participants were seated in a quiet environment in close proximity to their own microphone. This facilitated true interplay of participant input in a way that individual input would not have. I once more sought verbal consent from participants before recording, with a brief explanation of what group discussion would entail and that this would be the recorded portion of the session. Management of the recording is outlined in Section 4.5.2.

4.4.2.2. Semi-Structured Interviewing

The focus group was interviewed according to a semi-structured Interview Schedule outlined in Appendix D. The rationale for this was to ensure group members had the freedom for organic discussions that were not overshadowed by the drives and interpretations of the researcher (Birt et al., 2016), while also ensuring discussion remained on topic. One limitation to the fluidity of the interview was my monolingualism. In needing live translation of group discussion, some nuances and depth were lost in my understanding of how topics were developing.

4.4.3. Field Notes

Throughout the course of the groupwork, I made shorthand notes to myself regarding interesting points that emerged. These points were as follows:

- Prior to recorded discussions, during a break, participants discussed different dialect groups in isiXhosa, and that some isiXhosa-speaking individuals who come from far enough away sound like they are speaking a "whole new language". This poses a study limitation.

- A related point raised by my colleague is that some of the translations that were originally provided by Stellenbosch University represent a “deep”, rural form of isiXhosa that many urban-living individuals may not have heard before. Even though these terms would be the purest and most direct/’correct’ translation, this lack of familiarity means utility is lost.
- Much of the group was relatively young.
- Prior to recorded discussions, during the break, participants discussed how children with the type of issues noted in the A-TAC would either 1) just be seen as ‘kids-being-kids’ and perhaps just ‘in need of a smack’, or 2) that the children may seem just like their parents.
- During pre-group participant screening, child development seemed to be largely understood in terms of academic/educational terms.
- Some participants had a history of volunteer or support experience with children, with dyslexia as a concern being mentioned. However, when I commented on this, what was also made clear is that although children are spotted or experienced with these spheres of difficulty, no actual training or support is ever provided to help the facilitator intervene.

4.4.4. Data Analysis

4.4.4.1. Transcription and Translation of Interviews

The MLS assisted in the transcription process. Any points of discussion in isiXhosa were accurately described firstly in the source language and then translated into English. I worked with the English transcriptions when conducting the qualitative analysis. Given that there is a stage of translation here as well, both the Director and an assistant of the MLS assisted in the translation to ensure compromise in the final English text that was used in the analysis.

4.4.4.2. Analysis Process

A thematic analysis was conducted with the data. Although there is variation in what constitutes such analysis, I utilized a flexible, inductively driven approach as informed by the Braun and Clarke model provided by Terry et al. (2017) and Bryman (2016):

1. I used a process of familiarisation first, whereby the entire transcript was read-through and a comprehensive image developed. I also re-listened to the full audio.

2. I re-read the transcript, systematically generating of tentative codes line for line on a print-out.
3. The QDA Miner Lite qualitative analysis software was used for initial code clusters, and to re-organise and regroup codes as needed. These formed tentative, but distinct and congruent, themes. Drawing on the research focus, study aims matrix, and the inter-relation of code clusters, codes were nested within one another.
4. Names and definitions were given to themes, drawing on existing theory or literature as an interpretive guide, to derive ultimate themes and sub-themes. This led to final analysis.

Although theme construction was guided by theory, the inductive approach to coding ensured provision was made for new/unanticipated themes. Additionally, the coding strategy was reviewed by the study supervisor for confirmation of the themes derived. The concept of supervisory review of analysis falls in the vein of the 'coaching conversation' strategy in qualitative research (Maritz & Jooste, 2011). The supervisor is positioned to challenge a researcher to account for their coding choices and so reach deeper reflection regarding how the data has been analysed (Maritz & Jooste, 2011).

4.4.4.3. Evaluating the Veracity of Results

Given the fluid and shifting normative constructs that often form the focus of qualitative inquiry, certain guiding frameworks have been developed in order to evaluate the quality of qualitative output. One such facet is that research must hold 'trustworthiness', which is comprised of the following sub-criteria-sets (Bryman, 2016):

Credibility (*Feasibility*). Multiple constructions of social reality can exist at once – and in the process of the groupwork, a construction is also developed. Good research aims to ensure that results represent a credible account, version, or description of the participant's lived realities (Bryman, 2016). This aligns to Rubel and Okech's (2017) ideal research characteristic of 'data adequacy', in which results can only be based off good procedures, familiarising oneself with the research phenomenon, moderately (semi-)focused interview strategies and the collection of enough confirmatory data. To this end, I employed *member checking* as a strategy to ensure that analysis had not warped participant insights (Brit et al., 2016; Rubel & Okech, 2017), and to confirm that, after I had analysed the data, the participants were still able to "see their experiences within the final results" (Kristiansen & Grønkjær, 2018, p. 1805). This meant that

results had to be disseminated in a clear, simple and direct manner (Birt et al., 2016) (see Section 4.5.6). The document used to do so can be found in Appendix G.

Transferability. This reflects the degree to which results, derived from unique and contextual participant input, can be applicable to other (similar) contexts (Bryman, 2016). In essence, to reflect the applicability of results outside of the participant group. This is achieved through effective contextualising and description (Bryman, 2016). The literature on SA healthcare management, and the outline of the participants and the study procedures, help ensure the reader may discern how applicable results are to the future contexts they are compared to.

Dependability. This domain places responsibility on me at all stages to account for how I arrived at certain results and procedures (Bryman, 2016). Each decision must carry a justification. This arguably aligns to Rubel and Okech's (2017) ideal research characteristic of 'coherence' (methodological congruence), whereby the theory, epistemological frame and methodology are all logically aligned to ensure the integrity of results. All elements must be clearly stated, and any mixed methodology must be clearly rationalized. In Chapter 3, a full theoretical understanding of NDDs and the social-constructionist frame of analysis has been provided. The use of focus groups is congruent with both a constructionist perspective as well as the investigation of community norms surrounding NDD detection and awareness.

Confirmability. This is closely tied to dependability, in that, while accounting for how decisions were made, I should be able to evidence that I conducted the research in good faith and as far as possible tried to keep bias, inclination or objectives out of unduly shaping the research (Bryman, 2016). Subjectivity is always present in qualitative research, but the manner in which it emerges should be disclosed, and data integrity is thrown into question when one claims to have 'wholly removed' all elements of bias (Rubel & Okech, 2017). This ties into Rubel and Okech's (2017) research characteristics of 'subjectivity' and 'interpretive adequacy'. Subjectivity requires effective disclosure of bias from myself and continual awareness of how results may be reflecting said bias (Rubel & Okech, 2017). I do disclose preconceived bias in Section 5.4. Interpretive adequacy is hampered when immersion into data is not sufficient, leading to a biased, superficial reflection or simple rehash of the literature. This is combatted by clear quoting and paper-trailing for the analysis that I did (Rubel & Okech, 2017).

Aside from the trustworthiness of data, there is also the facet of 'authenticity' that research should hold. By this, what is assessed is whether research considers the political outcomes producing research, ensuring it does no harm while intending for the research to have some form of a pragmatic outcome or use outside the study itself (Bryman, 2016). Apart from producing a translated screen for clinical use, the current study aims to add to broader discussions regarding NDD detection in SA and to highlight, re-affirm or expand on areas of difficulty that need change.

4.5. ETHICAL CONSIDERATIONS

4.5.1. Permission of Relevant Gatekeepers

I retrieved permission to conduct research on the A-TAC from one of the screen developers in writing during his 2019 visit to SA. This document is provided in Appendix L. The translations of the A-TAC screen were commissioned by a PhD researcher towards an independent ongoing study in the Breede Valley. I requested permission for use of the Afrikaans and isiXhosa versions (see Appendix M). Study collaboration agreements were drafted between me and the MLS (see Appendix N & O). I undertook supervisory clearance and DESC review, followed by seeking ethical clearance from the REC:SBE of Stellenbosch University prior to the commencement of the study, ID PSY-2021-22178 (see Appendix Q).

4.5.2. Data Management & Security

The bulk of the data centred on participant opinions, as participants provided translation input and their perspectives on factors that hamper access and receptivity to NDD screening. Throughout the results and discussion section, participant identities are protected by way of the code 'Participant [P] 1-6'. Over SMS with each participant, names, ages, bank details for compensation, cellular provider details for data package sharing and screen question responses were gathered. These are not stored, and the chats have been deleted.

- **Data security**. Digital data includes the group translation input, the focus group discussion recording and the focus group transcription. Paper data includes A-TAC score sheets, consent forms, and transcription printouts. Paper data has been securely stored in a locked cabinet in the office of the study supervisor within the Department of Psychology at Stellenbosch University. Digital data has been securely stored on the Stellenbosch University OneDrive account of the study supervisor for a period of 5 years.

- **Data back-ups.** Print data has been digitized and stored with all other digital data on the Stellenbosch University OneDrive account of the study supervisor.
- **Raw data sharing**. I had access to all files throughout the process of data analysis, with copies stored on my own Stellenbosch University OneDrive. The MLS was provided a shared link to audio files on my OneDrive for transcription. This link had adapted settings to turn off downloads or link sharing. Following transcription, the link was closed.
- **Data destruction**. Once transcription and translation services regarding the focus group discussion were completed and handed over to me, the MLS Director was requested to delete the files from her laptop and email history. Participant SMS chains were deleted. Digital files backed-up to my Stellenbosch University OneDrive will be automatically deleted with the lapsing of my student account.

I still retain access to the participant's phone numbers. At the end of the groupwork, the participants of their own accord wished to create a WhatsApp group, to which I was added. This constitutes private arrangements between them, some of whom know one another by token of their children attending the same primary school. Contact details were not provided by myself.

4.5.3. COVID-19 Safety Protocol

All participants were provided the option of working from home and having their data expenditure pre-purchased. Each participant was provided their own classroom to sit in individually. Sanitizer was available and all pens, lunch packs and desks were sanitized. Participants were verbally asked on the day of the sessions whether they are feeling alright or have had any flu symptoms. The evening prior, all participants were also sent an SMS to remember to make sure they are feeling well if they want to attend the school for participation. Forms taken back from participants were placed in a bag and left for two weeks before being re-accessed. The cellular screening done the evening before comprised the following message:

- *COVID CHECK MESSAGE FOR TOMORROW:*
    - *Have you or a family member had a fever in the past week?*
    - *Have you or a family member been notably coughing or sneezing?*
    - *Have you or a family member had a sore throat?*
    - *Have you or a family member had any body pains / sore muscles?*

- *If you have been symptomatic, we will arrange that you can work from home by us covering your data use.*

4.5.4. Informed Consent and Voluntary Participation

All participants provided their free, willing, written consent to participate in the study. An outline of my goals was provided to participants in the study flyer as well as individually over SMS. On 31 July, consent forms were read with the participants and signed prior to the start of data collection. Consent was verbally reconfirmed with participants prior to the recording of the focus group discussion starting. The consent form, in both English and isiXhosa, are provided in Appendix C. On 4 September, the consent form was read over with the participants, and they provided their recorded private consent in the chat-box feature of Zoom. The consent form was presented with the exclusion of the focus group paragraph, as there was no interview for that day. The re-explication of the consent form was recorded, and this audio file has been stored on the study supervisor's Stellenbosch University OneDrive account as well.

4.5.5. Handling Potential Bias

Two main sources of bias can be highlighted. One element considers my own biases and how this may have impacted on 1) the manner in which questions were asked of participants and 2) the manner in which data is interpreted. The second element is that, in the course of translating the isiXhosa sections of the interview transcript, the MLS Director and her research assistant may have conveyed their own interpretation or bias into what was being expressed. Group participants engaged in frequent code switching between English and isiXhosa, and so I will be careful to make clear whenever analysis or results are being derived from a translated section of the transcription. Although having both the Director and her assistant was meant to temper this form of bias, it cannot be claimed to have eradicated it. Management of bias on my own part is partially addressed through reflexive disclosure. This is provided in Section 5.4.

4.5.6. Feedback to Participants

Feedback has been provided to participants. I compiled the final draft of the research results into a simple and clear to follow document that was shared privately with each participant (see Appendix G). As a member checking mechanism, the participants were asked to look at the results and confirm whether they felt it reflected their opinion or whether they felt adjustment was necessary. No alterations were suggested, and two participants indicated they loved how

neatly it pulled together everything the group had discussed. This document was thus treated as the final dissemination of results to participants.

4.5.7. Compensation of Involved Parties

The full budget outline is provided in Appendix P. Participants were compensated R50 per hour of participation, in addition to refreshments. The Vice Principal of the community primary school was compensated R600 (R100 per participant found). Although the Afrikaans focus group did not take place due to the study truncation, the assisting educator was nonetheless compensated R300 for his time. A donation of R1600 was made to the community primary school as thanks for the use (and unlocking) of the venue on two Saturdays as well as the use of the school's Wi-Fi. The MLS Director was compensated once-off as per private billing for her services in 1) translating documents, 2) venue arrangements, 3) co-facilitator services, 4) printing costs, 5) transcription services, 6) remuneration for the purchase of participant refreshments, 7) and all additional preparatory and reconciliatory work, as needed.

4.6. CHAPTER SUMMARY

In this chapter I outlined my protocols and procedures. Under the epistemological framework of the social constructionist paradigm, a cross-sectional, purposively sampled focus group of 6 isiXhosa speaking parents was recruited. Across two sessions, the group assisted in 1) adapting the isiXhosa translation of the A-TAC screen and 2) undergoing a 1-hour semi-structured, Zoom-based discussion regarding NDD detection and healthcare accessibility. The results of the discussion underwent transcription, translation, and thematic analysis. Themes derived were overviewed by the study supervisor and member checked by the group participants.

Chapter 5 will next address the results of both the language adaptation project for the A-TAC screen, and the results of the focus group discussion thematic analysis. A discussion regarding the results, and the implications and conclusions, will then follow.

5. RESULTS & DISCUSSION

5.1. INTRODUCTION

I set out to translate and adapt the A-TAC into Afrikaans and isiXhosa, and the isiXhosa version also underwent group input. I further conducted a thematic analysis of focus group discussions regarding parent perceptions of healthcare support and detection, NDDs and translated healthcare forms. In this chapter, I will provide findings gathered during data collection and analysis, as well as simultaneous discussion regarding how the findings speak to the broader literature. Finally, I will provide a passage of personal reflexivity towards the goal of transparency.

5.2. A-TAC TRANSLATION & ADAPTATION RESULTS

The final results tables for the translation work are attached. This includes: the isiXhosa worksheet, the Afrikaans worksheet, and a combined table comprising the final versions of each language decided on (Appendices I-K). Commentary is provided in these appendices, item for item, regarding meaning variations and negotiations. Smaller adjustments or additions, that did not require major structural revisions for an item, are highlighted in grey.

As emerged in the groupwork, not all sentences or constructs translate evenly. Steele and Edwards (2008), in their own isiXhosa adaptation of the Beck Depression Inventory, noted that certain constructs appear to translate smoothly because they "represent such basic and perhaps universal aspects of experience" and thus facilitates finding equivalent terminology in the target language (p. 212). Others, however, do not – and may simply reflect culturally nested experiences or priorities that exert influence the more 'open to interpretation' a sentence is (Steele & Edwards, 2008). In the current study, there appeared to be variation in how problematic different modules were to translate, i.e., clear distinctions between 'concrete' vs 'abstract' modules. Concrete sections were ones that did not require much adjustment and where the bulk of items were understood and carried the intended meaning. An example of this was the "Activity and Impulsivity" module (AD/HD), where items are framed in very concrete, visualizable and clear to translate 'scenarios' or 'examples', e.g., a child who cannot stay seated even when they are expected to. Other items fell to a more conceptual frame, e.g., a child being so engrossed in habit that it hampers their functioning. The manner in which these were negotiated is discussed below in Section 5.2.2.

Of the 81 total A-TAC items assessed, significant revision was required for 31 Afrikaans items and 31 isiXhosa items (38% each). However, it should be noted that the isiXhosa version contained two additional translation versions that were presented to the group to select from, without further revision being required. Of the 81 items, 58 of the final isiXhosa items were revisions different to the original isiXhosa version obtained from Stellenbosch University. This amounts to 72% of the screen requiring some form of revision or redrafting. This was because either the items did not capture the core meaning, or otherwise, more often, that there were means of more clearly or simply stating them. This correlates to noted difficulties in translation work for acquiring functional utility of a form (e.g., Colina et al., 2017; de Wet et al., 2020).

5.2.1. Systematic Adjustments

One systematic addition that was made throughout all isiXhosa screen items was the addition of the word ‘umntwana’ (“*the child*”). This is because in isiXhosa, the prefix ‘u-‘ is used to denote you, he and she, while in the English version of the A-TAC, questions were framed as ‘he/she’. Although the start of the screen, as well as each module, reiterates that the A-TAC centres on the child, I felt it was a safer option to include ‘umntwana’ throughout, so that the parent reader is continuously reminded that the question is focused on the *child’s* behaviour. The Afrikaans ‘hy/sy’ directly aligned with the English ‘he/she’.

A further procedural difficulty arose. I relied on groupwork to translate difficult items where there appeared to be confusion in meaning. Steele and Edwards (2008), in their own isiXhosa study, further found that the ‘committee’ structure was not always optimally effective for numerous reasons, including: disagreements between, and deference to, other members. In the current study, participants occasionally struggled to reach consensus on an item, or otherwise (especially drawing towards the end of the day) would defer to existing translations or the first suggested alternative. Sometimes, this meant that the confusion translated through into the new translations as well, with a related, but not direct, translation version offered. An example of this is how the group provided a translation regarding following *rules* (*imigaqo*) rather than following *instructions* (*imiyalelo*). The two are similar but create a definite difference in meaning. To counteract this, I did a final work through of the adapted questions with my isiXhosa Stellenbosch University colleague to gauge what she understood from the new items. Any adjustments made after this sitting were then cross-checked with the MLS.

5.2.2. Adjustments to Meaning

Aside from fixing grammatical and spelling mistakes across the A-TAC versions being reviewed, certain difficulties and debates arose regarding semantics. Some of these were merely synonymous phrases where preference was given to one over another, or where slight adjustments to phrasing or formality were needed. However, some produced significant divergence or miscommunication. It must be made clear that the current study procedures can only attempt semantic equivalence between language versions, and cannot assure construct equivalence without further research being required (Smit et al., 2006). In this regard, the current translation results only reflect an 'etic' conceptualisation of the A-TAC items, i.e., works on the assumption that the constructs contained therein carry across between culture groups in some form (Smit et al., 2006). Such a perspective validates the translation of psychometric tools rather than developing new ones from scratch for each language group. However, it does come with limitations (see Section 6.3). Some of the semantic difficulties that emerged were:

- **isiXhosa: *Unobuthathaka*** (*to have a weakness/sensitive response*) was provided for a child that is sensitive to sensory input. However, as emerged in the group, the ideal term to use will change depending on the context, with another variation being ***akazithandi*** *(to dislike*).
- **isiXhosa: *Qhubekeka*** (*continue*). Difficulty arose translating 'sustaining attention' and this term had to be inserted in a manner that reads as: 'to give attention and continue so'.
- **isiXhosa: *Uthethela ngesandi esibukhali*** (*speaks with a sharp sound*). This was the closest equivalent to the term 'talk in too high a pitch', as all other versions implied the child is simply being loud or outright shouting.
- **isiXhosa**. A significant adjustment to a query regarding compulsive thinking was between the unintended isiXhosa translation ***iingcinga ezingobumdaka*** (*dirty thoughts*), ***ezingobubi*** (*evil*), and the adjusted ***ubumdaka*** (*dirt*), ***usulelo*** (*infection*).
- **Afrikaans. *Uitgelok/onstel*** (*provoked/upset*). For the English term regarding whether the child is easily teased, this phrase was deemed preferable. This is because the more direct translation ***geterg*** (*teased*) appears to connote the passivity of a child who allows teasing to happen, rather than someone who is easily baited by teasing.

- **Afrikaans. '*Vertraag' vs 'Agterstand'*** (*delay*). 'Agterstand' was deemed preferable to 'vertraag', as the latter has taken on the same negative connotation as English, of 'retardation'.

Several occasions of decentering were necessary. This is when there is no elegant means of directly translating a phrase, and in order for the tools to still mirror one another, the original version is also adjusted (Jones et al., 2001). This may include additional words, additional examples, or alternative phrasing being used (de Wet et al., 2020), and is done because it is the smoothest means of achieving semantic equivalence between language versions (Smit et al., 2006). It represents a form of linguistic negotiation. In the current study, such examples include:

- **English: *Texture/consistency***. No adequate term could be found for this as an umbrella term in the isiXhosa group, and so an example had to be appended: '[…] or the *feel*/texture of things like a scratchy jersey // […] okanye baxa ukuva izinto ezinjengejezi erhabaxa?'.
- **English: *Sustained mental effort***. This phrase did not translate well and needed '/focus' affixed to reach adequate subsequent translations in Afrikaans and isiXhosa.

Idiomatic language was also a clear and predictable struggle during translation work. This is because such phrases are culture bound and do not lend themselves well to any literal translation into a new language, as the functional utility falls away (Steele & Edwards, 2008).

- **English: '*Ants in pants'***. This is an English idiomatic expression with no equivalent phrase in isiXhosa. To manage this, I compiled various definitions of the phrase, with the common theme being '*to be restless or agitated'*, and so it is this phrase that was translated into isiXhosa instead. This is congruent with the module in which it falls, 'Activity and Impulsivity'. Afrikaans, on the other hand, has a similar idiomatic expression, ***om rooi miere te hê*** (*to have red ants*).
- **English: *The child cannot be 'reached'***. This concept translated reasonably to Afrikaans with ***deurdring*** (*get through to*). It did not, however, translate well to isiXhosa, as it seemed to imply that the child is either not physically present or cannot be grasped at. The phrase ***awakwazi ukuthetha naye okanye ukumthomalalisa*** (*cannot talk to or soothe*) had to be used instead.

- **English**: ***'Flight of ideas'***. A unique sentence had to be constructed to ensure the sentiment carried through translations. For Afrikaans, this amounted to: ***sy/haar gedagtes vinning van een idee na 'n ander spring*** (*his/her thoughts jump quickly from one idea to another*) and for isiXhosa amounted to: ***nemfumba yeengcinga ngexesha elinye*** (*pile of ideas at once*). For the English version, ***flurry of ideas*** was appended as a more colloquial variant.
- **English: Keeping "on track" when speaking.** This required adjustment towards what sounded more naturalistic to each language. This includes ***te hou by die gesprek*** (*stick to the conversation*) for Afrikaans and ***ukugcina umxholo xa exelela*** (*keep to the topic when telling something*) in isiXhosa.

It must also be noted that the current translated screens cannot ever represent an authoritative final language version, as different dialectical varieties exist in different languages. As per my field-notes, the isiXhosa participants commented that certain varieties of isiXhosa, such as from different provinces, can sound like a different language. One such occasion in which this is noted is the difference between a 'high', 'deep', 'pure' or more rural isiXhosa (de Wet et al., 2020; Smit et al., 2006; Steele & Edwards, 2008) and urban, informal, and mixed-language forms of isiXhosa (de Wet et al., 2020; Makalela, 2014). Neither version can take priority, and while the current translations were developed in only one peri-urban context, the A-TAC would likely require tweaking as it transitions to different milieus.

- **isiXhosa. *Uhlobo lokwenza izinto mihla*** (*way of doing things daily*). This term is the closest colloquial equivalent of 'routine' that could be found. The 'proper' term originally provided is ***yimigaqo-nkqubo yemihla ngemihla***, but every single informant felt this was too 'deep' of an isiXhosa term that younger or peri-urban individuals would not know.

In this vein as well, two occasions of code-switching were required. Although I made clear that I would not make extensive use of code-switching in the methodology section, two items, under the module 'Tics' proved excessively difficult to translate and it was recommended that the English term be inserted in the question as well.

- **isiXhosa. *Uyandumzela* (*whisper*) / *uyagcuma* (*sigh*)**. The group could not think of a direct term for humming that did not share meaning with other concepts, and so it was recommended that the English '("humming")' be appended next to the term.

- **English**. ***Involuntary facial grimaces***. This term proved difficult in both Afrikaans and isiXhosa. The Afrikaans version decided on was ***onwillekeurige trekkings in sy gesig*** (*involuntary twitches/'pulls' in the face*). The isiXhosa version decided on was ***adlale ngobuso*** ('*playing faces'*) ***ingezo njongo zakhe*** (*without intention*), with the addition of the English '("facial grimaces")'.

5.2.3. Low Scored Items that were Retained in the isiXhosa Version

As a recapitulation, the groupwork functioned on a Likert Scale for the understandability of the A-TAC screen items. The scale ranged 1 to 5 with 5 being the best option of linguistic clarity. Where time allowed, items were assessed for semantic clarity or accuracy, but where time was not allowing, final items were included into the A-TAC final translation based on a majority vote ranking the item as 5 (i.e., four of the six individuals ranked the item as 5). However, owing to time and resource depletion, some items that fit neither scenario had to be included, nonetheless. Some of these were because parents agreed the item meant what it was intended to, and that they could just not put their finger on why the item phrasing did not work for them. For other items, there was no opportunity to re-address them. The full list of such items (with each participant's score attached) is:

- Item 34: Ingaba umtwana ulibazisekile ekufundeni ulwimi lwakhe, okanye akathethi kwaphela? [4,4,5,4,4,5]
- Item 42: Ingaba umntwana akanamdla wokwabelana ngovuyo, ngomdla okanye ngemidlalo kunye nabanye? [5,4,4,5,4,4]
- Item 55: Ingaba umntwana uneendlela zokuziphatha ezinyanzelisayo ezinje ngokuhlamba izandla zakhe, ukubamba izinto, ukuhlola izinto, ukuphinda-phinda izinto okanye iinkqubo, ukulungiselela okanye ukucwangcisa izinto, okanye ukubala? [4,4,5,4,5,5]
- Item 58: Ingaba umntwana uyasokola ukwenza nantoni na xa engekho ekhaya phakathi kosapho [4,5,5,4,4,5]

5.2.4. Focus Group Derived Input on the A-TAC

During the focus group, participants provided input regarding their outlook on the isiXhosa A-TAC, provided below. Given no Afrikaans focus group took place, it is not possible to generate likewise input. Sections that have been translated from isiXhosa are indicated by { }.

- "The questions are very good - for everyone. They are so understandable, and we as - I think we as parents **…** I think it's gonna work for everyone, even for the ones that - the one's that didn't go to school, they can understand the questions."
- "It is just that a few words that need to be change, which I am not happy about and are hard read and be understood, other than that, it's fine."
- "I think it would be much easier if it can be at the centre whereby if someone doesn't understand the question, they can ask the person sitting next to them "what is this question, can you explain this question to me?"
- "We never find people who ask us the questions that are asked […] so, most of the time it would be great if there was someone who was asking these questions{when you see there is something wrong with the child}."
- "The questionnaire was beautiful. It made me think of the other things that the kids{at home do that I thought were normal but aren't really}. {It has given} so much information, {this} questionnaire. I loved it."
- "{At the clinic I think this is where the questionnaire can work} […] If translated, {it can tell you whether the child has a problem}. If not translated, definitely{nothing can be correct} because {the} questionnaire{helps with} problems {of the} language barrier."

These statements indicate that the parents do hold receptivity to such a screening tool. They recognize the need for, as well as the existing lack of, such modalities wherein childhood concerns are queried. Once effective screen development has been enacted, it appears that the subsequent largest hurdle is in enacting the implementation of such screening.

5.3. FOCUS GROUP THEMATIC ANALYSIS RESULTS

The following section will present the results of the group interview thematic analysis. My goal, in addition to adapting isiXhosa and Afrikaans versions of the A-TAC, was to investigate factors of relevance to health screening processes for child NDDs. Specifically, I undertook to investigate parental perceptions regarding health and wellness detection, child development and receptivity to the idea of child neurodevelopmental screening. In this chapter, interpretation of the themes in relation to literature will be incorporated into the presentation of each theme and sub-theme, to facilitate more cohesive discussion. Four *major themes* emerged from the data, comprised out of two or more *sub-themes* linked under the same topic (see Table

3). Two such minor themes also had further *sub-themes* nested within them, touching points of greater specificity on the sub-theme (see Table 3). The structure of discussion will present each theme, their relevance, substantiation for the interpretation of the data in the form of italicised quotes, and interpretation of the content in relation to literature. Throughout the following section, passages that have been translated from isiXhosa are indicated by { }.

Table 2

Major, Minor and Sub-themes Derived from the Thematic Analysis

Category 1*: Clinical Dynamics Impacting Support and Detection		
Major Theme	Minor Theme	Sub-theme
Language Barriers	"It's a problem of language" ……..	"You don't understand what does it mean"
		"You don't know what the word is"
		"You feel stupid as a person"
	"It can tell you whether the child has a problem"	
Healthcare Disillusionment	"No one is explaining anything"	
	"It is not private anymore, everybody knows"	
	"It is always full, all the time"	
	"This is my responsibility to get across to people"	
Category 2*: Parental Understanding of Child Development		
Major Theme	Minor Theme	Sub-theme
Conceptions of Child Disabilities	"We tend not to think that the child has problems"	
	"After the trauma they cannot return to being themselves"	
	"People tend to think that people living with disabilities are stupid"	
	"The child is being bewitched"	
Management Routes Opted For	"You know the truth and you don't want to accept it"	
	"You need to help and monitor him" ……...	"We want to be monsters to our kids"
		"As parents we need reprogramming"

	"I suggest parents start at the school"
	"We just need to help the child navigate through life"

Note. The two categories listed were a means of relating the themes back to the research aims matrix and ensuring the themes held relevance in relation to the research purpose. The categories themselves are not thematically derived and are simply a means to group the Major Themes in relation to one another.

5.3.1. Major Theme: Language Barriers

Language as an emergent theme was not surprising, as it was one of my foci. However, the way in which it emerged was broader than anticipated. As outlined in Chapter 1, the research Question 2 aimed to investigate parent perception regarding translated documents they receive in their community. This domain diverged early on, as the group participants made it clear that they rarely received such translated resources. Instead, what emerged was a theme of extensive verbal communicative barriers that hampered healthcare detection and overall engagement.

5.3.1.1. Minor Theme: "It's a problem of language"

This category spoke to the participants' experienced absence of isiXhosa in the healthcare system. The three sub-themes represented related, and yet unique, difficulties and outcomes that stem from such a communicative barrier. A summative discussion will be included following on the sub-themes to interpret the data in relation to existing literature.

Sub-Theme 1: "You don't understand what does it mean". This sub-theme was one in which an inability to understand the doctor or health clinician was discussed. Two of the fathers indicated that, within this theme, the untranslated materials they are provided with are ineffective, as the documents are not understood.

> *"And sometimes […] at {the clinic} they do give you {the pamphlet}, "read this, read this" – yeah, you can read something but as a parent you don't understand what does it mean?"* (P5)
>
> *"If [documents are] not translated, definitely nothing [discussed] {can be correct}."* (P6)

The above quotes highlight that even though attempts may be made in the healthcare setting to provide some form of information, the parents "don't understand" the material. As a result, "nothing" discussed with regards to the content of the materials "can be correct" or

represent a precise form of input from the parents. A related concept was highlighted with the quote:

"Most medicine is not written in isiXhosa […]" (P5)

The idea of medication not having translations was raised by one father in the context of parents having limited awareness of what treatments exist for their children. This once more highlights Xhosa parents as being left in the dark regarding what management routes are available because they cannot build such an awareness for themselves when language acts as a barrier.

"[The] doctor – she's a Indian or a young White or a young Coloured lady. Obviously, she won't be able to speak your language …" (P5)

"It's a problem of language, where [the parent] can understand" (P4)

"And then if the person {he can't speak} English […] they can't hear what [the doctor] says is wrong with them." (P1)

Finally, two fathers raised the above points with regards to the clinician's inability to communicate with parents. The theme very clearly derives from the existence of a "problem of language", wherein the clinician is often not a native isiXhosa speaker and does not hold enough functional proficiency in the language. Owing to this language "problem", the parent who "can't speak English" cannot follow what condition(s) may be present. This speaks to a lack of clarity.

Sub-Theme 2: "You don't know what the word is". A related, yet distinct, struggle regarding language difficulties at the public healthcare clinics concerned the parent's ability to express themselves. Two parents, in particular, emphasized that it is not just a difficulty of understanding the English or Afrikaans doctor, but also in trying to express the difficulties you view in your child in English. One mother raised an example of being unable to express epileptic symptoms to a doctor, with a fellow participant responding in agreement with an example of the difficulty, as below:

"{The language is then a struggle because you don't know what the word is for an 'Epileptic Seizure' in English.}" (P1) – *[Participant response:] "Shaky-shaky, jumps."* (P5)

Another example was provided by one of the fathers about a case he knew regarding someone else's child. School personnel had attempted to contact external (health) professionals,

who indicated that it did not sound like anything was wrong with the child. The father suspects it was because the personnel were unable to express enough accurate information regarding the child's difficulties, noting it as a "language barrier" issue:

> *"{But when [the school] called external people, they said nothing was wrong with the child … but maybe it was because of a language barrier and a lack of information.}"* (P6)

The current theme was most concisely summarized by the father at the end of the group interview. He expressed that there would always be a (linguistic) "barrier" that will hamper parents from properly expressing what their children's difficulties are, because as non-native English speakers, they are unable to convey the correct sentiments.

> *"{There will always stay a} barrier between the health care worker and the parent and {we as parents will not find it easy explaining something that is wrong with the child because of this issue.}"* (P6)

Sub-Theme 3: "You feel stupid as a person". A sub-theme that added a new dimension to language difficulties experienced at the clinics was one in which parents experience a sense of shame, denigration, or indignation because of the existing language barriers. One mother especially raised the difficulty of feeling stupid (and being made to feel stupid) for not being able to follow what the doctor has said:

> *"{You don't know English, maybe you don't know Afrikaans – you feel stupid as a person"}* (P1)
>
> *"{You find them asking why you do not know English at this age […] so now they will take you from the consultation room into the corridor just so they can embarrass you in front of everyone and make you feel stupid}"* (P1)

The above indicates a sense of shame that is interwoven into not being able to speak English (or any other language the clinician speaks) proficiently. What is further highlighted is the fact that the health clinician is viewed as being a denigrative figure, actively setting out to "embarrass [the parent] in front of everyone" because the parent is struggling to understand and making the parent "feel stupid." This sentiment was carried by other participants

> *"{When you ask the doctor what they said, they tend to make a spectacle of you.}"* (P1) – *[Participant response:] "Exactly, stigmatized!"* (P5)

[Quoting the doctor:] "How come we don't understand this?"(P3)

In response to the mother's elaboration that the doctors make a "spectacle" of the parent, other group members provided their confirmation of this experience. At the least severe level, the doctor is perceived as unempathetic, not understanding why the parents "don't understand" what they are explaining. At worst, the sentiment of the clinician being an actively denigrating figure is repeated, one in which the parents are "stigmatized".

"I don't see any reason why people must be ashamed of {their home language}. If you don't understand {something in their language}, you have a right to ask."
(P1)

Finally, the above sentiment outright recapitulates the sense of shame, or feeling "ashamed", of their home language. There is also a sense of indignation, where there is an awareness that a parent has "a right to ask" the doctor questions. As an additional research note, the element of indignation especially came across in the tone and emphatic nature with which the participants expressed these sentiments at the time of the interview. This was just as apparent when re-listening to the audio recording.

Summation of Minor Theme: "It's a problem of language". This minor theme was comprised of three independent and yet related sub-themes. The image that emerged across these sub-themes is that clear language barriers exist. In the public clinics, healthcare clinicians are often unable to speak isiXhosa, and instead consultations (and informative materials) are presented in English or Afrikaans. This leads to an inability for Xhosa parents to understand what is explained or what condition(s) is present. Parents also struggle to express themselves due to this barrier and not knowing the correct words to express in the doctor's language. The parents are thus unable to provide sufficient or accurate information regarding the difficulties their child is experiencing. In addition to this, the parents experience a sense of shame of this language barrier, feeling "stupid" for not being able to understand or communicate effectively. Finally, the healthcare clinicians are perceived as managing these communicative barriers in a denigrating fashion, setting out to "embarrass" the parent, make a "spectacle" of them or making them feel "stigmatized".

This is relevant, as health screening and intervention is impacted by contextual factors, as discussed in Chapter 2. This includes parental perceptions. The results are confirmed by research

that indicates that very few healthcare clinicians can consult with a client in isiXhosa and thus the condition conveyed to the client would be impacted (Solomon et al., 2012). Indeed, a Tshwane study confirmed that one third of public healthcare patients misunderstood the instructions provided to them (Fernandez et al., 2014). This language concern further results in parents feeling unable to express themselves or feel accurately understood.

An additional element of concern is the theme of language stigma and shame. In an inverse study to the current one, Schierenbeck et al. (2013) assessed factors that hamper mental healthcare access from the perception of healthcare staff. What emerged was difficulties such as shame stemming from patient reluctance to attend clinics (or to comply with medical prescriptions) and patient weariness regarding the stigma surrounding mental health topics. In a study of patient HIV treatment experiences at public clinics, healthcare staff likewise expressed feeling like the patient's constructed sense of stigma was the largest difficulty (Bogart et al., 2013). Inversely, patient participants expressed public healthcare humiliation, such as having their serostatus discussed in front of other people, and perceived nursing staff to be hot-tempered, disrespectful, and uncaring (Bogart et al., 2013). Whether intentional or not on the part of healthcare staff, the experience of shame on the part of the patient will serve as a definite deterrent to seeking treatment and is important to address. While language barriers emerged as a common thread across the literature, I could not find any that seem to address *language* as a topic of shame in clinics, and this may form an interesting avenue for future investigation.

5.3.1.2. Minor Theme: "It can tell you whether the child has a problem"

This second minor theme related to the topic of Language Barriers highlights the utility and need for translated materials and additional translation modalities. The majority of participants brought up, in some form, that translation services are required in order to affect healthcare support. One father provided the following quote:

> *"If i-translated, [a document] {it can tell you whether the child has a problem} […] {because the questionnaire helps with} problems {of the} language barrier"* (P6)

The father here promotes how translated screens and forms can promote awareness of child difficulties and parent understanding. However, the quote also took place in the context of expressing that it can overcome the language barrier. In this context, translated documents not

only allow doctors to gather the information they require, but it also allows the parent to point to, and express, the difficulties they have seen in their child when they are "{explaining something that is wrong with the child}" (P1).

> *"We are coming [from] areas where we speak our native language isiXhosa […]"* (P5)
>
> *"The [A-TAC] questions are very good, for everyone […] I think it's gonna work for everyone, even the ones that didn't go to school, they can understand the questions."* (P3)

The two points of input above appear to reflect two clear and simple concepts when understanding healthcare services. The first is that these are parents within Xhosa communities, speaking their "native language", and in need of materials that do likewise. The second point is that, within said context, such ideal tools should reflect a simple version of a translation, *accessible* to the broadest base of people – as even those who "didn't go to school" should understand it.

> *"{When you go to a healthcare facility […] the nurses that work at the particular clinic, when there is a parent who has problems with language, maybe there should be someone to help them translate.}"* (P1)
>
> *"I think we need more people, like, at the clinics […] {let there be a designated individual who is the translator.}* (P3)

Finally, two mothers also brought up the need for verbal translation assistance as well. Both draw on the idea that at the "healthcare facility", there should be someone clearly demarcated to assist parents with translation and understanding, whenever parents experience a language barrier.

Thus, what emerged in this theme was parental need for access to more isiXhosa translation modalities. These would be both in the form of live verbal assistance and simple, accessible versions of translated health forms. The benefits derived are perceived as opening better communication avenues and allowing parents a means of properly expressing the difficulties they experience with their children. In a context where mental health literacy is low and difficult to convey (Schierenbeck et al., 2013; Sorsdahl et al., 2012), healthcare tool translation is promoted by the SA government as necessary (Franz et al., 2018). Within the

United Nations AAAQ healthcare framework, such form translation would also fall within the 'Accessibility' tenet that all individuals have the right to seek and receive accessible forms of health information (Schierenbeck et al., 2013). With regards to live translation services, while certainly necessary, this may prove more difficult given the established staff shortages at public health clinics (Braathen et al., 2013). Therefore, alternative avenues such as lay-community volunteers may need to be investigated (Bradshaw et al., 2006).

5.3.2. Major Theme: Healthcare Disillusionment

This major theme captured several facets and factors that represent difficulty engaging with the healthcare sector – particularly, public healthcare centres. Such factors represent a barrier to effective treatment, leading to parental dissatisfaction. The sub-themes listed emerged out of the discussion surrounding ideal screening tool administration procedures (as per Question 1) and expanded to broader health service themes in the same manner that language as a theme did. These sub-themes ultimately confirm findings that (mental) healthcare service provision is markedly under-provisioned in SA public healthcare settings (Ashley-Cooper et al., 2019; Braathen et al., 2013). Once more, the relevance of such themes to the study focus is the indication they provide of hurdles that serve as a deterrent to parental engagement with healthcare processes. These further represent a breakdown of the process of building mental health literacy. This major theme is captured by the quote: "{[*The healthcare staff] should be aware of what people experience in the clinics, they should know.*}" (P1).

5.3.2.1. Minor Theme: "No one is explaining anything"

This theme once more encapsulates the perceived lack of clarity, now due to a lack of effort put into explanations from healthcare staff. Parents elaborated that they are not provided with sufficient information when attending the doctor and leave without a good understanding of what is required. Such a scenario was fully painted out when one of the fathers described:

> *"[The doctor] will give them medication, and they will pay, and no one is going to say 'Mama, you see this, this medicines is for this and this, and this is the side effects' – no they don't do that […] no one is explaining anything to them."* (P4)

What is highlighted in the above example is the emphasis that there is sometimes a complete lack of any attempt by healthcare staff to provide parents with understanding. The

participant views no information as being conveyed because the doctors simply "don't do that". This is further elaborated by a second father:

> *"{If a person gets medicine or an injection, they leave without a good understanding of} what the doctor said."* (P5)

Once more, medication is highlighted as not being properly explained, with the extension into injections as well. What is highlighted is a lack of clarity, as parents do not have a "good understanding" of what was said. This is in the context of not only general consultation but the responsible use of medication. The difficulty with clarity is contextualised as sometimes relating to a language barrier, in which there is "no space" provided for the doctor to communicate to the parent, as below. This indicates a bridge between the two spheres of difficulty.

> *"So sometimes there is no space for our parents to – for someone to explain to them."* (P5)

What is reflected here is that parents experience little or no understanding or explanation of the clinical processes occurring around them. This at times may reflect language difficulties but at others appears as a complete lack of an attempt at any explanation on the part of the clinician. Not only may this deter parents from seeking interventions that will not be explained to them, but it also precludes the development of condition- and mental-health literacy. This theme reflects previous SA literature, in which patients indicated that they experience no guidance or explanation (Braathen et al., 2013). The lack of explanation regarding medication-use or what additional management routes to follow has also previously been found (Braathen et al., 2013). This has arguably been one facet contributing to what healthcare staff note as 'medication reluctance' on the part of patients who do not trust the prescription given to them (Schierenbeck et al., 2013). In a Cape Town observational study looking at mental health literacy in epileptic patients, Keikelame and Swartz (2013) report that there are numerous occasions in the public health sector in which opportunities to provide patients with explanations are not pursued by nursing staff.

5.3.2.2. Minor Theme: "It is not private anymore, everybody knows"

The following theme reflected sentiments of lacking any privacy in the public healthcare centres, with the implication of possible diagnostic exposure and sense of scrutiny. The clearest

example tying these facets together in this theme is the following quote provided by one of the mothers:

> *"[There are] people who know when your name is being called on Room 9, you are going to take chronic for HIV, so when you are being called on Room 5, you are going to take i-treatment for TB"* (P1) – *[Participant response:] "Because it is not private anymore, everybody knows."* (P3)

Certain spaces in the public clinics are indicated by participants to have grown associated with certain functions. The result is that privacy is precluded while one's diagnosis may be estimated by other patients because "everybody knows" what the functions of different sections of the clinic are. The sense of scrutiny implicit in such a dynamic was highlighted by one of the fathers:

> *"It is full {at the clinic}, inside and outside – people are watching you, like there is something wrong with you […] {some of us are sensitive}."* (P5)

Such a sentiment indicates that in addition to the public health centres being packed "inside and outside", there is a visceral sense that others perceive there is "something wrong with you" or that they want to figure out what is "wrong with you". The reference to individuals as "sensitive" may reflect that such an environment is an affront to one's sense of privacy. This is further relayed in the following passages:

> *"Sometimes as parents, it is not easy to speak out, or – {you are trying to explain and there are other people}."* (P5)
>
> *"The person [healthcare staff] who is gonna ask will say 'Eh, sis, do you understand this [pamphlet]?' and sometimes she is asking you and there are other people around you – and you're gonna say '{Yes}, I understand', not – {I don't want to look dumb}."* (P5)

The final passage further references a sense of shame attached to the perceived scrutiny. There is a fear that one may end up looking inept or "dumb" in front of other patients if queried in the open by a healthcare staff member. In the context of the above passage, this also tied into a sense of shame surrounding being able to understand non-translated documents.

Thus, a lack of privacy here is interwoven with elements of fear of scrutiny, fear of disclosure and a fear of public shaming (which has already been discussed as an element that

may arise). Patients at the public healthcare centre are concerned that they are being watched, and that personal difficulties will be inadvertently exposed. In relation to this topic, (P1) gave an excellent summative statement: "*That is why people no longer feel safe to use [NAME] clinic*". This statement provides direct evidence of healthcare access difficulties and discomforts serving as a deterrent to treatment seeking. Such issues of privacy and diagnostic exposure have been noted for difficulties such as HIV-infection (Bogart et al., 2013), and avoidance of clinics due to fear of stigma regarding mental health difficulties has also been confirmed (Schierenbeck et al., 2013). Another element to bear in mind is that in the context of NDDs, parents in Xhosa communities may be blamed as bad parents or judged for their child's oddness or misbehaviours (Guler et al., 2018). In a context with a lack of privacy, negative attention is not only directed at the adult, but their child as well. An additional reference worth mentioning is one mother's (P3) sentiment regarding the negative nature of attention drawn to the child: *"{at the clinics, they can make our children feel so small}*."

5.3.2.3. Minor Theme: "It is always full, all the time"

As evidenced in the name, this theme reflects a lack of capacity at the public healthcare centres to manage the volume of people in attendance at once. One father, to the agreement of several participants, raised a point that clinics are simply busy, and you will always have to wait:

> *"There is going to be no space because the majority of people are going inside."* (P5)

> *"Because, another thing, going back to the clinic, is not easy, {you will not be first, and there will be at least 10 people. No, you come and there are} other people and it is full."* (P5)

In addition to highlighting difficulties with space, the concept of "going back" to the clinic, mentioned above, represents a further interesting aspect. The father brought up this point in the context of not receiving sufficient information from the doctor, not knowing how the medication works, and now having to return to the clinic for a doctor or nurse to assist with clarity. The lack of capacity is also outright understood in terms of economic disparity:

> *"{At} public clinics, it is not the same like the private sector, or Medi-clinic – {it is always full}, all the time."* (P5)

As the quote for which this theme was named, it is emphasised that public and private healthcare centres are different in both the nature and in the provisions that they can make for an attending patient. The participant appears to raise the comparison of an implied quiet or ordered private hospital, with the "full" public clinics. However, 'busy-ness' is not only associated with the clinic space, but also the healthcare providers themselves:

> *[Description of healthcare staff:] "[…] {someone who is going to leave, who is maybe at a desk inside and tells you} 'I have a patient inside'."* (P3)
>
> *[Quoting the doctor:] "'I have a lot of queue outside', yeah."* (P1)
>
> *"{You are right […] the doctor will have an excuse they give a person […] they will not explain to people and will just say that they are tired and that, no, they have other patients and so cannot help}."* (P6)

As indicated in the first quote above, in the context of discussing what additional services are required at the clinics, and the role other health or social welfare professionals may play in this, one mother described the healthcare staff as people who will "leave" because they "have a patient" to see. This was re-affirmed by another mother who confirmed doctors will express they have a long "queue" and so cannot be of further assistance. This was most strongly reiterated by the father in the third quote, who saw what the doctors express as "excuses" in order to not have to explain or assist further.

What was referenced in this theme was the participant's perception of a lack of capacity at the healthcare centres to assist optimally. This takes the form of either full or cramped spaces, long waiting times, or implied unsatisfactory, short consultations owing to doctors needing to see many more patients yet. This once more speaks to how the healthcare spaces these parents experience are under-provisioned (Braathen et al., 2013). The public healthcare sector experiences an established shortfall in terms of staff, with general nurses and lay healthcare workers managing most functions of the clinic on a time and resource deficit (Braathen et al., 2013; Bradshaw et al., 2006; Schierenbeck et al., 2013; Sorsdahl et al., 2012). This means that very little time is available for any given patient attending the clinic (Braathen et al., 2013).

There is a further shortage of available rooms at such clinics (Schierenbeck et al., 2013), which in addition to being understaffed, means the clinics experience a service backlog. The shortage of available rooms also raises interesting considerations discussed in the previous

theme, regarding patients "who know" what different rooms are intended for and may read a diagnosis into someone attending such a room. There is the arguable extrapolation that parents may worry, not only regarding what diagnosis may be read into a room, but what 'mis-diagnosis' other parents may read into attendance of a room.

5.3.2.4. Minor Theme: "This is my responsibility to get across to people"

This theme centres on who should enact healthcare detection procedures around the child – and parents as their own empowered detection agents emerged in the course of analysis. In this regard, the theme refers to what routes are held to be an ideal 'first' point of contact or 'desired' alternative step in developing a parents' awareness and facilitating observation of the child. Note that I draw a line here between detection and management, which is a separate theme. Such discussion was interesting not only for its content, but its progression as well. Starting from discussion based in the healthcare clinic, the conversation diverted to new involved professionals and new venues. Specific improvements for healthcare staff were not raised.

> *"I think we need more people, like, at the clinics, more people like social workers […] {a person that knows that 'this is my responsibility to get across to people} […] I am translating for people, people need to understand this'}."* (P3)

In the above comment, the concept of designated, 'go-to' individuals at the clinics to support parental clarity is reiterated. However, this time what is suggested is that it instead be a social worker. Whenever parents are confused or in need of explanation or translating, this would be a designated individual whose "responsibility" it would be to assist. I also interpreted a need for reliability as embedded in this conception: with someone who has a "responsibility" to meet the parents' "need" to understand. This need for support was further reiterated. When queried how screens like the A-TAC be administered, the ideal was to have someone present for support and clarity:

> *"If someone doesn't understand the question, they can ask the person sitting next to them 'what is this question, can you explain this question to me?'"* (P4)
>
> *"Even if not inside the clinics, maybe a container outside – maybe there is going to be two or three people who are sitting there."* (P5)

As indicated by the concept of the "container outside", this is a concern that also speaks to difficulties around space and privacy, with designated individuals serving the parent's needs

for clarity. It is also indicated below that parents do not as yet have such individuals asking (A-TAC) NDD centred questions, and thus the first step towards detection and support is not initiated.

> *"We never find people who ask us the [A-TAC] questions that are asked […] If we had people that asked these questions when you have a child initially [the parent would consider potential problems]".* (P2)

Although it is not specifically outlined above who the "people" would be that would enact such queries, the statement was raised in the context of parent denial around child difficulties, and the need to improve parent awareness. This, when viewed with the following quotes, speaks to parents wishing to be effective detection agents for their own children:

> *"It is our job to observe our kids and look what the child's problems are."* (P3)
>
> *"I am the one {that can see that} maybe my child has a problem."* (P3)
>
> *"Most of the time {the child is truly seen} first by the parent and then the parent decides [how to manage]."* (P2)

As an alternative to clinic attendance, what was brought up several times was the role of the parent in detecting difficulties with the child. The mothers expressed that "I am" the one whose "job" it is to "look" and "decide" what problems the child may have. What also stood out from the final quote was the notion that "*then the parent decides*". In this context, parents wish to direct how issues with the child will be managed, and for functional detection to start with themselves. They hold agency in their child's management. Additionally, two participants indicated that, in the course of building their picture of the child's struggles, they would first seek consultation with the school or teacher, prior to attending a healthcare centre.

> *"I think I would first go to the teacher, find out how is the child in the class."* (P3)
>
> *"{Myself}, I believe in one thing, {when you notice the child has funny actions, go to the school}."* (P6)

This theme's common element is an implicit desire for bolstering of parental awareness, agency and detection of child concerns. This necessitates support structures, including having "more" people to help with explanations and understanding, school-based feedback on how the child is performing "in the class" and to present parents with the right questions to help focus their concerns. It then becomes the parents "job to observe" and then decide how to manage this

situation, including when to collaborate with medical intervention. This is further substantiated in the upcoming themes "*As parents we need reprogramming*" and "*We just need to help the child navigate through life*". In the current theme, where discussion incorporates the healthcare centres, it does so through an idealistic lens, rather than reflecting on existing practice. This also raises important considerations regarding whether the healthcare centre is the first or only venue at which screening such as the A-TAC should be initiated.

When I relate the findings to existing literature, the comment that parents are not currently being provided NDD avenues of questioning is congruent with NDDs not being a core focus of ECD intervention programmes. Aside from tangential relation to supporting early developmental delay and bolstering learning programmes, the NDP 2030 prioritizes a different set of mother-infant concerns (Ilifa Labantwana et al., 2019). Mental health difficulties are less addressed than other health concerns despite the WHO call for "no health without mental health" (Sorsdahl et al., 2012, p. 168), This also speaks to the current need for such NDD screening.

With regards to the desire for social worker or school supported detection avenues, this reflects a call for task shifting child health detection out of the healthcare centres (Bradshaw et al., 2006; Sorsdahl et al., 2012). With regards to schools being a parents first route for child feedback, this raises the suggestion that perhaps parent opted, child health screening is better placed at schools, and even preschools and ECD centres, so as to enact the earliest possible detection. DoSD and DoH stakeholders certainly have posited a need for better inter-sectorial collaboration for enacting early screening and intervention (Franz et al., 2018). Such avenues would just require that lay school staff or social workers receive adequate mental health training (Bradshaw et al., 2013).

On a point of methodological reflexivity, it should be noted that within the data, topics of detections, support and intervention are interwoven. In line with my goal of assessing factors related to child health and wellness *detection*, I have created a delineation in such discussions. This delineation relates to content that speaks to *detection* specifically, versus elements that relate to broader healthcare, management, and intervention practice. Although this neatens the data, it does also draw such discussion/perspectives more into the realm of abstraction – and so risks losing some of the more reflective, 'muddied' dynamics that occur in practice. It is

recommended that the minor themes "*This is my responsibility to get across to people*" and "*We just need to help the child navigate through life*" be read in conjunction with one another.

5.3.3. Major Theme: Conceptions of Child Disabilities

Several different conceptions of NDDs could be delineated from the commentary of the parent participants. These are necessary to investigate, as they impact parent perception regarding the cause and management route to be pursued. It should be noted that the focus group interview took place after the participants had already spent the morning doing groupwork to adapt A-TAC items. Thus, in the following analysis, conceptions of child difficulties that appeared to be 'once-off' references were discounted. However, themes that repeated themselves are discussed below. Similar to what has been noted by Khonje et al (2015) regarding dementia in Xhosa communities – lay constructs of mental health categories appeared to take on an amorphous definition that tie together different streams of ailment or difficulty into one.

5.3.3.1. Minor Theme: "We tend not to think that the child has problems"

This first minor theme centres on the seeming lack of awareness that exists on the part of parents around developmental difficulties or NDDs in children. At the base level, this comprises the scenario in which it never occurs to parents in the first place to "consider" NDDs:

> *"So, we tend to not think {that the child has problems}."* (P2)
>
> *"At the time {that the child has AD/HD}, you didn't sit and consider things like that […] [Parents] don't take into consideration that {there is such an illness}."* (P2)

This element of "consideration" was a repeated concept for this mother. She notes that NDDs or developmental difficulties are not something that forms a part of decision making when it comes to conceptualising the child, or management of the child. The element of 'management' also emerged in the following excerpts. Specifically, what emerged is that, even if difficulties arise and are recognized, they are not treated as developmental concerns:

> *[Regarding punishment:] "[…] not knowing that {that they are troubled}."* (P3)
>
> *"We are quick to judge {our children for their mistakes}, not taking into consideration that some things, they are part of {the} development {of the child}."* (P1)

In the first quote, the mother spoke in the context of smacking a child for wetting the bed, "not knowing" there may be developmental difficulties causing the bedwetting. The behaviour is noticed, but the explanation considered is not developmental. The second mother reiterated a similar point, noting that a parent will judge their child, not "taking into consideration" that the issues may be developmentally rooted. Related to this point was parents noting that knowledge does not exist around developmental themes:

> *"So, there is a lack of knowledge of these illnesses in black communities."* (P2)
>
> *"{We are} ill-informed about things like i-autism."* (P2)
>
> *"I think we are just too ignorant."* (P3)
>
> *"So other medicines that are – that can be used to cure other illnesses that is happening with children around the home, we don't know anything about that."* (P5)

Words such as "lack of knowledge", "ill-informed" and "ignorant" were used to describe the lack of mental health literacy perceived to exist in the community or "black communities". Additionally, one father highlighted that there is also a lack of awareness for treatment methods or "medicine" to help with the child "around the home".

What arose in this theme was a lack of awareness regarding child developmental difficulties. NDD concerns may not be noticed by parents, and even when behaviours manifest that may be cause for concern, these are not interpreted within an NDD frame. While the need for parent training will be discussed in a different theme, the participant commentary is consistent with research findings of poor public mental health literacy in SA (Braathen et al., 2013; Kakuma et al., 2010; Schierenbeck et al., 2013). This may lead to an unnecessarily long route in seeking support and intervention (Dixon, 2015). Once more, one can point to the fact that such ECD awareness raising campaigns in SA do not centre on NDD concerns, especially in early childhood (Ilifa Labantwana et al., 2019). In addition, ECD programmes experience greater implementation barriers in under-resourced communities to start with (Ashley-Cooper et al., 2019). This and the theme "As parents we need reprogramming" raise the need for improved parent outreach and education programmes. If parents are not aware of NDD concerns they may not be inclined to engage with detection processes surrounding NDD detection for their child.

5.3.3.2. Minor Theme: "After the trauma they cannot return to being themselves"

This theme, in different forms, conceptualise child behavioural difficulties as stemming from emotional difficulties. Two parents expressed that when environmental stressors and significant events have occurred to the child, the resulting emotional turmoil that the child experiences could become the explanatory framework.

> *"Maybe try and recall a time when the child got some traumatic experience that maybe made the child develop things […] {because some things are caused by trauma in their mind, then after the trauma they cannot return to being themselves}."* (P2)

In the above quote, child difficulties are indicated as possibly stemming from a "traumatic experience" the child has had. Although the nature of such trauma is not elaborated, it does appear to refer to the child displaying a post traumatic anxiety response (APA, 2013). A variation of this was elaborated for the example of a child being bullied:

> *"We notice {he sometimes urinates while sleeping […] when he sleeps, he seems to be in the playground, then his mother also says he could be dreaming about what was happening to him because he is bullied} […] "{The child cannot report what happens to parents because they are scared}."* (P5)

Here, the father elaborates that fear and turmoil around the child being "bullied" can translate into behavioural symptoms such as bedwetting. The emotional turmoil of the child is emphasized, wherein they are so "scared" of their bullies that they cannot even report to the parents what is going on. Finally, emotional struggles stemming from the child's home life have also been highlighted by both parents:

> *"If the parents put stigma on what is going on with the child, the child then {when they go out} … {it starts in the home}.* (P2)
>
> *"{You take out the anger you have because the child's father didn't take care of you, and so on.} Now you have a new boyfriend, you have a second child, the old child is going to take a back seat."* (P5)

With regards to the first quote, the mother took a pause in the middle of her statement, which means the content needs to be extrapolated from the context from which it was drawn. The mother was discussing that if parents stigmatize their child and outright treat the child "like

something is wrong" with them, this impacts on the child. Although it is my interpretation that the *impact* referred to is on the child's emotionality or behaviour "when they go out" – it is clear that the mother interprets poor parental treatment "in the home" as influencing the child. One father provided the further example, in which a mother "take[s] out her anger" on the child or forgets about the old child when starting a new family. This once more represents a turbulent household dynamic impacting on the child.

Emotionality, anxiety, and emotional turmoil were raised as possible explanatory factors in a child's behavioural difficulties observed. This includes major traumatic events or repetitive sources of distress inside and outside of the home. As a starting point, I consider this completely fair to be considered as a possible explanatory framework. All mental healthcare difficulties of childhood are not necessarily NDDs – and mood, eating, conduct and attachment difficulties can also be representative of independent psychosocial disorders (APA, 2013). However, it is important to note that these are all also comorbid or resultant domains related to NDDs to a greater degree than would be expected by chance (Anckarsäter et al., 2008). Thus, NDDs may still be necessary to consider, even where emotional stressors are present.

On the note of a turbulent household dynamic impacting on the child, this has also been noted as a concern of parents in literature. In one ASD study, parents expressed fear that others would blame their child's difficulties on bewitchment or because "bad things happened in our house" (Guler et al., 2018, p. 1009). Furthermore, poor parenting, child maltreatment and low parent education have been demonstrated to increase the progression of antisocial or externalizing behaviours, including in NDD-risk cases (Beauchaine et al., 2010; Selinus et al., 2015).

5.3.3.3. Minor Theme: "People tend to think that people living with disabilities are stupid"

At the base level, this theme reflects the view of the child who struggles with academic or intellectual functioning. However, it also takes on deeper levels of disease stereotypy. When participants draw to mind an image of NDDs, they mention elements of poor academic functioning, poor learning and outright stupidity:

> *"But people tend to think that people living with disabilities are stupid."* (P1)
>
> *"{Other children are slow learners […]}"* (P1)

> *"Some of the kids {they have} – they are having a lack of learning, they are having a lack of speaking, they are having i-lack of behaviour and moving and all of that."* (P3)
>
> *"[…] there is a reason why {they got expelled from the school they attended}."* (P1)

The above quotes outline an image of the child as a "slow learner". This is further elaborated by the idea that there is a reason the child would be "expelled" from a mainstream school. This would appear to touch on LDs. However, the topics of changing schools and the child being "stupid" highlight and additional conception that incorporates IDD:

> *"{They said nothing was wrong with the child and he should be in mainstream school}."* (P6)

This is once more reiterated by one of the fathers, who indicates that in one case he knew of, the child was recommended to remain in mainstream school. This suggests the opposite opinion was held for the child – that a child with signs of neurodevelopmental 'oddness' does not belong in the mainstream schooling system. Two mothers spoke outright about the child needing to go to a 'special school', Dorothea:

> *"{Once a person sees the child has 'abnormal behaviours', they think that, wow, the child is disabled and is going to bother me and must be taken to a 'special school'}."* (P2)
>
> *"{Once the child is looking diseased, we say 'Oh, your child you've made needs to go to Dorothea [special needs school]}."* (P2)
>
> *"{We as parents don't know if we think that at Dorothea [the children] can read or if that bunch is taught ABCs}."*(P1)

This brought up several elements of note. In addition to the implications of the child having IDD and possibly not even being able to "read" or be "taught the ABCs", there are also elements of phenotypic syndromes and shame incorporated here. Firstly, there are references to a "person see[ing]" the child's abnormal behaviour, and the child "looking diseased". This implies outward signs of disability or noteworthy severity of the NDDs. Additionally, the quote regarding the "child you've made" incorporates a sense of blame and shame placed on the parent of the child.

It is apparent that in this conception of child developmental disabilities, LDs and IDD are hybridised to form an image of the child that is a poor academic performer, possibly does not belong in mainstream schooling, and has a possible complete "lack" of capacity to learn or be taught the "ABCs". In addition, the children are perceived as being outwardly readily perceived as disabled. I can only speculate that this encapsulates both appearance and severity of behaviour, as "abnormal behaviours" and "looking diseased" are both mentioned. Finally, there is a sense of blame placed on the parent who birthed a child with such difficulties. These results are understandable, as most NDDs are behaviourally defined and difficult to interpret (Dixon, 2015; Stephens, 2012). What the group appears to reference is specific indicated syndromes (such as Down's Syndrome), which may have high overlap with NDDs (Sharma et al., 2018), including difficulties such as IDD and a related increase in epilepsy (Besag, 2017). In my own field notes, at the pre-group screening stage, it was noted that participants seemed to largely understand child development in academic or educational terms.

With regards to blame placed on the parent, there is precedent for such belief. In an isiXhosa, Khayelitsha based study, parental explanations of IDD in children included factors of pregnancy, factors of birth delivery, and spiritual factors (including bewitchment or ancestral displeasure) (Mkabile & Swartz, 2020). A parent being blamed for poor self-conduct during pregnancy may feel shamed. This forms a link to the theme regarding a need for privacy in clinics. Although not a part of the analysis, two noteworthy quotes from parents included: "*Comparing kids, yah*." (P2) and "*We have the attitude where you see that we admire other people's children*." (P5). In a context where such comparison occurs, with no clinical privacy, a parent may experience concern that the child will be judged by other parents to be 'mentally deficient' if they were to catch word of developmental difficulties, and that the parent would be shamed.

5.3.3.4. Minor Theme: "The child is being bewitched"

This theme was interesting both for its emergence and subsequent suppression. There was one instance in which it was expressed that parents may view the child's behavioural difficulties as being caused by witchcraft. This theme is brought up, not necessarily due to its repetition in the data, but due to its potential pertinence to the research question:

> *Most of the time black parents also {will say something about the child being bewitched […] in the throat because they are eating nothing, or they are then made very hyper}."* (P2)

In the above passage, the witch is implied to have impacted on a specific part or function of the child's body. This includes bewitching "the throat" which cause the child to "[eat] nothing". However, there are two further facets brought up. The first is that the phrase "most of the time" is used to describe how this parental explanatory model is rather prevalent. Furthermore, this explanation is understood as being specific to "black" SA parents.

The above point is strongly backed by research that suggests witchcraft may form an explanatory model in Xhosa communities (e.g., Matshabane et al., 2020; Mkabile & Swartz, 2020; Khonje et al., 2015). This may then imply intervention routes centred more on the support of a traditional healer (Braathen et al., 2013; Khan & Kelly, 2001; Khonje et al., 2015). The participant above did not state whether this explanatory model was her own belief or not, however, despite the apparent prevalence of this viewpoint, the concept barely featured in the study. It is possible that owing to me being a white male, parents did not want to speak about the topic of bewitchment (or other topics such as ancestral anger) because they felt I would not understand or agree with them. Thus, the current study can only claim to touch on the healthcare perspective of parents when such discussion is enacted through Western biomedical discourse.

5.3.4. Major Theme: Management Routes Opted For

In juxtaposition to healthcare detection, this major theme relates to the pathways parents may take to address issues they observe in their children. The management route one opts for would depend on previous thematic domains noted, including how the child's symptoms are understood by the parent. This in turn would determine whether parents would pursue, or be receptive to, NDD screening.

5.3.4.1. Minor Theme: "You know the truth and you don't want to accept it"

This theme relates to a parent's possible inactivity or disinclination to address their child's difficulties. Overall, the perception is that a parent would hold some form of suspicion that something is wrong with the child but would then opt to ignore it or otherwise explain it away whilst not taking any pro-active steps forward.

"We are too procrastinating, because you know the truth and you don't want to accept it." (P1)

"We know something is wrong, but we keep quiet, or we just sit back knowing there's something wrong happening with the child." (P3)

"{You don't want to think} that your child is special." (P2)

As reflected above, parents of children with NDDs are perceived to know the "truth" and to know "something is wrong". This situation is then, however, dealt with through passivity when a parent "just sit(s) back" or procrastinates. The possible explanation provided for such behaviour is a parent that is in denial, who does not want to "accept" or "think that" the child is "special". This passivity is highlighted by one mother as even extending into situations where the parent is called to action regarding their child:

[Description of some parents:] "[…] {when the child does something at school, you act like you don't know when you actually follow what happened}." (P1)

In this quote, the parent is accused of actually being aware of their child's behavioural difficulties and understanding what the child would have done at school, but choosing to act unaware so that they do not have to address it. Additionally, one father gave an example of how difficulties may be explained away:

"[Something] we do as parents without realizing is that thing where you have so-and-so's child who is clever and gets 10/10, and then your child who get 6/10 […] {we say that no they are dumb} like his father or uncle." (P5)

Parents may blame any shortfall their child experiences as them just being "dumb" like a family member. From my own field notes, what arose prior to recorded group discussion was children may just have difficulties explained away as "kids-being-kids" or seeming like a parent. This arguably places the child is in a situation where there is no further requirement towards intervention.

Parental denial and inactivity appear to stem from an avoidance of accepting that the child may be "special". Parental lack of awareness may be one explanatory factor for this (Dixon, 2015), wherein either not enough is known about child development so red flags may be excused away, or so that the severe conception of NDDs remain the benchmark against which the child is compared. Shame may be another factor. Parents may be unwilling to engage of the

societal stigma regarding their child's disabilities (Guler et al., 2018), or be blamed as parents for negligent or abusive parenting (Guler et al., 2018), or otherwise for poor pregnancy management or upsetting the ancestors (Mkabile & Swartz, 2020). This theme most arguably correlates to the theme "We tend not to think that the child has problems" as a resultant management route. The reference to children being like their uncle or father also demonstrates explanatory models based on the inheritance of behavioural traits from family members, as has been researched with other heritable conditions in Xhosa communities (Matshabane et al., 2020; Solomon et al., 2012).

5.3.4.2. Minor Theme: "You need to help and monitor him"

As an inverse to the previous theme, this minor theme covers the ways in which parents might pro-actively set out to manage the child's symptoms or behavioural difficulties. Linking to the prior major theme that emerged around healthcare disillusionment, it must be noted that, once more, healthcare centres are only considered one among several routes to be taken. In this regard, they are also not necessarily the first route that will be opted for. Although the following two quotes will be broken down and analysed within the sub-themes, they serve as a cohesive summation of the participants' view of the intervention pathway:

> *"I think I would firstly go to the teacher, find out how is the child in the class […] and then from there mos, most of the schools, maybe they have psychologists and all that, then I will ask them to help the child […] then if maybe they can't, then that is when you go to the social worker to try and find help."* (P3)
>
> *I suggest {parents start [at the school] and then they go to the clinic or meet a social worker}."* (P6)

On the parent-initiated intervention journey – if developmental difficulties are suspected, the parent would first go to the school. If further steps are needed, they would seek social and health support, but with public clinics serving as a final resort. A summative discussion will be included following on the sub-themes to interpret the data in relation to existing literature.

Sub-Theme 1: "*We want to be monsters to our kids*". This sub-theme relates to the parent's use of punishment or other forms of discipline as a means of managing the child. The implication herein is that behavioural difficulties can be conditioned out of the child. Two mothers expressed discipline-oriented views, in which children as a pattern are expected to bend to their parent's wishes for their own good:

"{We want to be monsters to our kids – they are afraid […] you're a monster because of your actions} because one of {the reasons} […] is to protect them from {things in the world}." (P1)

"We expect that kids must change their lives to adapt to whatever we want them to do." (P2)

The concept expressed above, of being a "monster" to their child to "protect them from things in the world" was interpreted as referring to parental discipline, akin to the sentiment of 'tough love'. The implication is that a parent must be tough with the child in order to get them ready for life, ready for difficult dynamics and managing themselves properly. The second mother expressed how children were to "adapt" as desired by the parents.

"{We as parents like to give the child a smack when they wet the bed, even before they are age 5}." (P3)

In this example, there is a clear indication of punishment, the "smack", being used in an attempt to curb problematic behaviour. In my field notes, it must be mentioned too that sometimes children with behavioural problems were mentioned as just "needing a smack".

Sub-Theme 2: "*As parents we need reprogramming*". This following theme encapsulates the parents desire and perceived responsibility to improve their awareness regarding child development and the symptoms their own child presents with.

"So {we} as parents we need reprogramming." (P2) - *[Participant response:]*

"Reprogramming on how to develop the child's brain. Because sometimes it is not the child's brain that is under-developed – it's the parent's." (P5)

As a counterbalance to the previous theme, the sentiment above reflects a need for more information and more training. The parents above describe parents as needing their sometimes "under-developed" brains "reprogram[ed]". This reflects the need to understand the child better, to view them and the ways of supporting them through new eyes, and with more information. Developing such awareness is placed as the "responsibility" of the parent:

"I think it is the responsibility of the parent that they need to research the child's disability." (P1)

"Be aware and understand, and if the parent *understands the child's situation, then they know how to help."* (P1)

> *"I think for us as parents, it is our job {to observe our child and to look what the child's problems are, and what do I as a parent do if my child has struggles?"* (P3)

It is described as the "job" of the parent to develop insight into what their child's difficulties are, to observe and understand the child, to do "research" and figure out "what to do as a parent". The implication of the above, however, does also include the parent having noticed the "disability" or "problems" and taking further steps to be supportive. Thus, a first step of parental awareness building is still required. One father discussed the need for training of children and teenagers, however the points raised may be reflective of the training dynamics more broadly:

> *[In the context of child training:] "Because in our community, we don't have social workers or {the} centres where they will teach […] so we need people from {Stellenbosch University to train people to do these things}."* (P5)

The father here brings up that there is a current lack of resources (both with regards to space and personnel) present in the community for effective, large scale training programmes. The need to have trained individuals external to the community come in (such as from "Stellenbosch University") was raised in order to combat this current lack of capacity – at least insofar as personnel.

Sub-Theme 3: "*I suggest parents start at the school*". The school has already been discussed as one of the alternative detection routes parents may utilize in order to build a picture of their child's difficulties. However, it was also raised as a first point of management as well:

> *"I suggest {parents start at the school}."* (P6)
>
> *"I'm the one who needs to go to the school to address the problem of my child […] {my child is here to learn so the teacher} has to understand what is happening to my child."* (P3)

The school is perceived as the venue that will "start" to "address the problem" of the child, so long as the teacher can "understand". Implicit is also that the parent's first point of concern would be for the child's academic functioning, as it is stated by one mother that it is her responsibility to make such arrangements because the child "is here to learn". However, the

wording also suggests an implicit responsibility on the part of the teacher to support the child, as she "has" to understand. However, further hopes are placed in the school with regards to support:

> *"{And when you go to the school, I think indicate that your child has a disability on the school forms, so that the school can maybe help and watch the child}."* (P1)
>
> *"Most of the schools, maybe they have psychologists and all that, then I will ask them to help the child."* (P3)

One mother indicates awareness of the concession routes that schools are willing to allow through the use of a "disability form". Although it must be noted that what is not reflected in this statement is the fact that a formal diagnosis would first need to be established for use of such forms. Nonetheless, it reflects hope that the school would be able to "help and watch the child" and thereby action some sort of support. Another mom raises the hope that a school would function with allied health support staff such as school "psychologists". This links to avoidance of the healthcare centre difficulties which lead to avoidance and healthcare disillusionment in the first instance.

Sub-Theme 4: "*We just need to help the child navigate through life*". This theme demonstrated the parents' need to collaborate with healthcare workers towards supporting the child, even if this is a reluctant collaboration. This theme is distinct from the detection stage, and the wording used by parents implies that doctors would be consulted once difficulties have already been spotted and conceptualised. Barring school support being enough, parents would seek out a social worker, possibly prior to considering attending the healthcare centre:

> *[If the school cannot assist:] "Then they go to the clinic or meet a social worker}."* (P6)
>
> *[If the school cannot assist:] "Then that is when you go to the social worker to try and find help."* (P3)

Once it becomes necessary to seek the help of the doctor, the parents would then attend the healthcare clinic. The first quote below, from which the theme title is derived, was raised in direct relation to all the issues of the healthcare centre that were raised under the theme of healthcare disillusionment. The statement represents a need, for the sake of the child, for both the parent and the healthcare worker to collaborate optimally:

> *"The healthcare workers and, uh, the parents have to find {an} understanding […] {there must be, I don't know, some middle-ground} […] we just need to help the child navigate through life with whatever they have as a challenge."* (P2)

The implication of the above is that parents are coming to the healthcare worker out of necessity, not preference, and there is the implicit request that both sides find a way to simply work together effectively and find some "middle-ground" to plot a management route forward for the child. A further implication is that the parent is at the clinic because they have already spotted "challenges". This thread in also carried in the quotes of another mother:

> *[Visiting the doctor:] "You need to know what is happening, if he is having fits or seizures – and how you need to help and monitor him."* (P1)
>
> *"I think it is your responsibility to tell the doctor about 'I have noticed this and this and that about my child."* (P1)

In both passages, the parent is indicated as already knowing what difficulties need addressing. The parent sees there are symptoms such as "fits" and is in a position to tell the doctor "I have noticed this and this". Rather than a broad assessment, the doctor is sought for management of a clear sphere of difficulty. There is also the implication that after the management plan or further referral, the healthcare professional will not constitute as a continued mode of support:

> *"{Maybe the doctor gives you feedback that the child has speech problems and refers you to consult with a speech therapist, then it is your responsibility now as the parent to understand how speech therapy is going to help}."* (P1)

It is indicated that once the parent is "refer[red]" to a new professional, it becomes the parent's responsibility once more to know what is happening and how the professional "is going to help". This relates to a previous point in which parents feel it is their responsibility to build their own awareness regarding what is wrong with the child. However, I also submit that there is an implicit stance here that the parent will not get said understanding from the healthcare professional. This ties back to an earlier observation that parents leave clinics without an understanding of what is going on.

Summation of Minor Theme: "*You need to help and monitor him*". This minor theme was comprised of four related yet distinct sub-themes. On one hand, parents may wish to shape

their child's behaviour, and provide effective discipline towards preparing the child for life. This may or may not include punishments such as a "smack" for problematic behaviour. On the other hand, a parent may seek support for developmental difficulties understood as such. These routes included 1) the parental responsibility for one to improve their awareness of child development. The hope is that this would facilitate better observation and support of the child. Such insight would aid the parent in taking the next steps towards detection and management. 2) Parents also place hope in the school as a starting point for supporting the child. This includes ensuring that the teacher is able to support and monitor the child to facilitate better learning. It also encapsulates the hope that schools would be staffed with their own internal health- and allied staff to help the child. Finally, 3) healthcare staff are engaged with when it becomes a necessity to do so. The hope on the part of parents is that all involved parties can work through the health centre difficulties for the sake of the child. Parents approach doctors with specific observations and concerns in mind, for which they seek advice on the correct management route moving forwards.

The four above mentioned themes, laid out in the order that they are, arguably represent a chronology of the management routes parents undertake. The starting point would be the use of discipline, because child behavioural difficulties would be seen as wilful misbehaviour and 'naughtiness' on the part of the child (Guler et al., 2018). Guler et al (2018) highlight that community members may see the child's NDD behaviour as a reflection of poor parenting and the child not being taught correct manners, which parents may wish to avoid by enacting punishment.

A divergence from this is the next theme, in which parents wish to receive better clarity and training surrounding child development. While this was partly framed as the parent's responsibility, the question then becomes where would parents receive such materials on their own to read up for themselves? Indeed, from my own field notes, one participant who volunteers to assist dyslexic children commented that, even when it is known that the child has a developmental struggle, the facilitators are not provided training or support with which to enact intervention. Such training would likely need to be provisioned by lay workers and community volunteers as a context-appropriate modality (Bradshaw et al., 2006). With regards to Xhosa community ASD training of the Early Start Denver Model for parent coaching, contextual

difficulties were internet access, translations and conveyance of complex concepts, time limitations, and context-insensitive training materials (Makombe et al., 2019). However, this was in relation to intensive intervention training for parents of children with diagnosed ASD. It is possible that more introductory or surface level training initiatives may still be effective.

Parents indicated they would opt for school support before medical support for a child. This is understandable, as schools may represent a more familiar venue with educators who have more robust insight into the child, in comparison to others. The need for school staff training has already been discussed in the theme "This is my responsibility to get across to people". School serves as an alternative to the healthcare clinics. However, it should be noted that there are limits to the types of support a school can provide. Certain avenues, such as medication and formal diagnosis, would still necessitate the healthcare centres.

Parents finally hold a reluctant need to collaborate with healthcare staff and doctors when other management routes have not been enough to support the child. This reluctance arguably stems from all the factors encapsulated in the theme "Healthcare Disillusionment", including a lack of privacy, healthcare staff being perceived as denigrating figures, long waits, a lack of information provided, and other factors (Bogart et al., 2013; Braathen et al., 2013; Schierenbeck et al., 2013). Parents attend with implicit request that health processes be conducted properly for the sake of the child. Indeed, the following additional point of commentary highlights the parental dissatisfaction and desire for reform:

> *"I think if the parents and the health care workers can be put together and sort of like having a debate, so that ii-parents they can raise their concerns about the healthcare workers […] {They should be aware of what people experience in the clinics, they should know}."* (P1)

The difficulty herein is that NDD intervention is highly under-provisioned in SA (Braathen et al., 2013). In addition, public healthcare staff do not hold adequate training in mental health difficulties, and considering time and capacity constraints, are unlikely to be able to engage effectively with such training (Braathen et al., 2013; Bradshaw et al., 2006). This means that parents are still likely to experience difficulties around the management of their child's case. This had led to calls for further research into how intervention modalities may be implemented by non-specialists in an appropriate fashion (Sorsdahl et al., 2012).

5.4. POINTS OF REFLEXIVITY

I currently work at the NDC as a training co-ordinator in neurodevelopmental topics, as well as an assistant to a researcher completing their PhD in NDD detection. From my work, I see the confusion and difficult referral routes families go through to understand and help their child**,** even within the private sector. This motivated me towards the current study, as it was my belief that such parental difficulties would be exacerbated in the public sector, where fewer resources are available. However, both work experiences and existing literature bias me towards viewing NDDs as a topic of shame, dread, and confusion for families. I was thus particularly sensitive to latent themes of stigma and shame in the data.

My own training history into NDDs, as well as my own Western cultural upbringing, biases me towards a biomedical understanding of such conditions. This emerged in the conception of the study, as initial questions, per the interview schedule, were focused on the public healthcare clinical setting, rather than alternative avenues. This is seen in the question: *Do you feel that a parent would be able to answer a form like this alone, or only with the assisted reading and explanation of a healthcare professional*? While schools and social work emerged as alternative avenues in the focus group, more biomedically divergent themes did not, in particular. For example, although I anticipated traditional healing practices, ancestors and witchcraft may emerge in the study, only one brief reference was made to witchcraft. It is possible that me being a white male (in addition to presenting a healthcare-focused talk) induced participants to discuss child development in more biomedical terms as well.

As a middle-class, white male in SA, I come from a privileged background in comparison to the participant group setting. Additionally, it is important to reflect on the unequal power relations that may have potentially been at play. Namely, paying participants per hour for two full days to participate meant I occupied the temporary role of ‘employer’. As an overall monolingual English speaker, I was also in need of translation services to track discussion, which placed me further in the possible position of being a somewhat detached observer of interactions. The above-listed elements may have served to create a disconnect between myself and the participants, resulting in the possible: 1) desire for participants to please, or alternatively; 2) reservations of participants around fully opening up about certain topics. Finally, I am not myself a parent. My perspectives on child development and child NDD difficulties may more starkly

delineate red flags and domains of impairment. In practice, parents likely occupy more of a grey zone in which behaviour warranting true concern must be more gradually teased out.

5.5. CHAPTER SUMMARY

In this chapter, I discussed the findings for the two arms of the study. This included 1) the translation work findings and reflections (including difficulties with abstractions, idioms and group processes, and the need to employ decentering, code-switching and exemplification), and 2) the focus group feedback from participants, the key themes derived from said feedback, and a discussion of the findings in light of existing literature. My findings demonstrated language barriers and healthcare reluctance, a multiplicity of perspectives on childhood NDDs, and the need for alternative avenues of support.

Chapter 6 will provide the final conclusive summation of study findings, according to each arm of the study as well as conjointly. Study limitations and recommendations are further provided.

6. CONCLUSIONS

6.1. INTRODUCTION

I aimed to 1) pursue a mixed-methods workgroup to adapt and translate language-appropriate versions of A-TAC screen items towards NDD screening; and 2) to conduct a focus group to elaborate themes of NDD detection and child development. This was in order to broach the theme of SA NDD screening accessibility from a side of *supply* (i.e., an existing adapted screen) as well as the side of recipient *demand* (i.e., regarding health and wellness detection and support services, child development and receptivity to the idea of child neurodevelopmental screening). This chapter covers final summation of the study findings, the study limitations, and recommendations to be made. This includes both 1) discussion regarding translation outcomes and challenges and 2) the outcome of the thematic analysis of the focus group interview.

6.2. SUMMATION OF STUDY FINDINGS

6.2.1. Conclusion of the A-TAC Translation Domain

On the side of *supply*, I translated and adapted Afrikaans and isiXhosa versions of the A-TAC. Both sets of screens underwent initial forward- and back-translation, as well as a source language monolingual judgemental design. The screens were handed to of my two colleagues, who drafted their own adjustments of the items. For the Afrikaans A-TAC, the item versions were deliberated with additional colleagues of mine. For the isiXhosa A-TAC, the screen underwent a ‘committee’ deliberation with isiXhosa, home-language speaking community participants across two days.

Of the initial translations that were provided to me, 38% of the Afrikaans items and 72% of the isiXhosa items underwent significant revision or redrafting. This emphasises that translation work in SA is fraught, especially with regards to isiXhosa. Items were checked both for consensus on the clarity of items, as well as to ensure they carried the correct semantic meaning. The results work on an etic assumption that the constructs contained in the A-TAC can be carried over, cross-culturally, into the target language. The more abstract or idiomatic the item, the greater the level of work that was required to adjust the item. Due to depletion of time and resources with which to conduct the study, four items (numbers 32, 42, 55 and 58) of the isiXhosa A-TAC have been retained, even though consensus could not be reached on the clarity of the items. Neither the Afrikaans nor the isiXhosa A-TAC should be taken as a final

authoritative version. When extended to new community contexts, the items would need to be reviewed to determine if they are a good fit for the local dialect.

With regards to achieving the goal of *supply*, the current study thus produced a carefully deliberated set of NDD screening questions in Afrikaans and isiXhosa. As established in Chapter 1, there is a current lack of adapted, multi-domain screening tools in SA. Given the established overlapped nature of NDDs, such a tool is necessary to query several symptom domains, towards possible assessment and intervention, at once. The current study has provided the first step necessary towards conducting second stage validation research on the translated screens. Such translations, although not yet empirically indicated to be predictive, could tentatively be used towards building insight for clinicians into suspected child NDD cases.

Furthermore, Question 1 of the current study was as follows: *What is the reception of participants to the [A-TAC] screen and its ideal administration procedures*? During focus group discussions, participants held a favourable view of the screen. They indicated that it would be overall understandable and would help parents consider domains of difficulty they might not otherwise have done so. Such sentiments indicate parents do hold receptivity to such screening tools. This likewise assists in clarifying a portion of study aim 2, regarding parental receptivity to child neurodevelopmental screening. The parent participants recognized the need for such a tool.

6.2.2. Conclusion of the Focus Group Thematic Analysis

On the side of *demand*, I sought to investigate themes of participant sentiments towards childhood NDDs and healthcare detection. Existing research has spoken to the perspectives of parents with diagnosed conditions in terms of their psychoeducative and intervention journey (e.g., Guler et al., 2018). Few studies in the SA have directly investigated the NDD perspectives of parents without such an indicated child. The current study may thus speak to themes and perspectives in the larger, non-diagnostic community. A focus group lent itself well to a constructionist perspective – thus developing a transient normative framework that touched on broader discourses and social influences. Participants co-created and agreed on their understanding of the social forces impacting healthcare management in their community, elaborating how perspectives and behaviours of the child, clinicians, community members and parents themselves enact certain processes and outcomes. These will be discussed below.

Several themes regarding neurodevelopmental detection and support arose. As noted above, Question 1 queried what ideal screening tool administration would entail. What emerged from this line of questioning was an expanded domain of healthcare difficulties and barriers perceived by the participants, and the alternative routes they would opt for as a result. Question 2 was originally conceptualised as: *What is the nature of translated documents that parents receive in the communities*? Given the lack of translated documents received in the community, the theme that emerged instead centred on the absence of isiXhosa in the public healthcare setting. Themes regarding language and healthcare barriers assist in clarifying the portion of study aim 2, regarding the perceptions and dynamics of health and wellness detection for NDD children in the given peri-urban setting. The relevance of such themes is that significant hurdles to health detection may serve as a deterrent for parents to engage in such processes and deteriorate the process of building mental health literacy.

As such, language barriers were perceived by participants to be a significant hurdle to health-services, as doctors predominantly do not speak isiXhosa. This entails parents may be unable to understand the clinicians, instructions or forms provided to them. Parents may likewise struggle to express the child's difficulties. A need raised in this regard is the presence of accessible translation modalities or appropriately adapted documents. Within the history of SA's medical resource disparity, participants spoke to broader elements of lacking effective clarity in this healthcare setting. This is affirmed by discussion in Chapter 2 and the resultant call from governmental stakeholders for translation work (Franz et al., 2018).

However, additional hurdles sour participant engagement with the clinic system. Parents expressed being made to feel ashamed for not understanding the clinician's language properly. This was a novel element not robustly found in the literature. Parents further experienced clinicians as making no effort to bolster clarity during sessions. This may reflect at times a perpetuation of the language barrier but on other occasions appears as a perceived complete lack of an attempt. Research suggests that health staff miss key opportunities to provide patients with insight (Bogart et al., 2013), and the participants appear to speak to this idea of clinical disinterest and confusion.

Whether intended by the clinician, or over-inflated by the patient – if healthcare staff are experienced as disrespectful, aloof or unempathetic, it erodes trust in healthcare processes and

creates disillusionment. In this vein, parents described staff-, room- and resource-shortages that create a lack of capacity to efficiently manage the number of patients. This was explicitly tied into economic disparity discourses, as public and private clinics were compared to each other. Packed public spaces become zones in which one may experience shame or fear of diagnostic exposure.

Such a lack of privacy and resulting shame is congruent with existing literature (Bogart et al., 2013; Schierenbeck et al., 2013). Developmental difficulties may be conceived of as stemming from emotional turmoil (such as trauma or maltreatment). Otherwise, the child's developmental difficulties may stereotype low intellectual functioning, poor learning, and burden. This was referenced as speaking to a broader discourse of the 'special' child, and phenotypically identified 'disability'. Participants noted that parents love to compare one another's children. In the clinic, where there is a lack of space and privacy, parents may worry the child's struggles will be discovered and judged. There is also a sense of blame that may be placed on the parent, such as for birthing a child with such difficulties, managing pregnancy poorly, maltreatment of the child or otherwise failing to teach the child manners. This speaks to narratives of agency, and misbehaviour as resulting from mismanagement, abuse, or misconduct. One additional explanation that did not place the burden of blame on the parent is that a child's behavioural difficulties may be caused by bewitchment.

However, parents may also fail to recognize neurodevelopmental difficulties in their child owing to a lack of awareness or poor mental health literacy. There may also be denial on the part of the parents, who do not wish to think their child is 'special'. This may then lead to inactivity on the part of the parent, and a failure to engage with detection or management systems. This may tie to the use of discipline to manage the child, as behaviours are once more conceptualised as wilful.

However, participants acknowledged a societal lack of awareness driving parent decision making. Parents indicated themselves as responsible for learning about child development. This also spoke to the parents' desire to be informed agents who can detect difficulties in their child and deliberate the management routes. Within this ideal of empowerment, the first stage would be for support structures (such as translation services, training programmes and school feedback) to be in place. This may necessitate lay workers and community volunteer support. Possibly

owing to deterrent healthcare centre factors, the clinic does not appear to be the prime detection route.

On such an empowerment route, the informed parent may ideally approach the school first. At a detection stage, teachers are a source of informed feedback on the child compared to peers. Thus, schools may serve as an important locale for screening. This may lead into a school-based management route. In this regard, schools may support the child, make concessions, and direct the child to any internal health or social services. If the school cannot be of assistance, participants indicate that a social worker would ideally be approached next. Parents appear to hold a reluctant need to collaborate with healthcare workers at the intervention stage. The hope expressed is that, for the child's sake, clinic processes function properly, alluding to healthcare disillusionment. Intervention outside of clinics, in the hands of non-specialist volunteers, is one posited alternative.

I achieved my goal of unpacking parent perceptions surrounding healthcare detection and conceptions of NDDs. With regards to detection, although parent's indicated receptivity to NDD screening, they also raised barriers and the desire for alternative routes and training. In answering the second portion of Question 1, ideal screening administration appears to implicate schools. This holds implications for bolstering multi-sectorial engagement. Furthermore, language *shame* as a theme was unexpected and worth future unpacking. Lastly, despite indication by a participant that witchcraft may be an explanatory model for NDDs, this topic was not further raised in any other point of the group discussion. Study results should only be read as reflecting parental views within a biomedical framework.

6.3. LIMITATIONS

Linguistically, the fact that the translation work only represents an 'etic' stance of translation can be critiqued. It assumes that constructs hold the same 'shape', components and weighting between languages and cultures, if they exist at all. Thus A-TAC items are built on a Western biomedical foundation. While this may raise the argument that tools should be developed afresh for a community, rather than adapted – this would be resource-intensive. Additionally, given the lack of research on NDDs, it is hard to know how such conditions should be re-conceptualised between different groups. While such research is necessary, the current study aims to fill a gap at the intersection of: 1) a need for NDD screening and; 2) a dearth of SA

NDD research. On a related note, when a sentence cannot be directly translated and an approximation must be developed, there will always be a level of subjectivity in deeming the version adequate or not. By undergoing repeated review, research and application, the A-TAC will be able to be further optimized.

Owing to varying geographic and community dialects that exist in isiXhosa, another language limitation is that I cannot claim to have produced an authoritative isiXhosa version. When applied to a new context, the translations would have to be reassessed to determine whether they are appropriate for the given context. The current study was developed with a particular community context. It is hoped that this provides a starting point for the development of a more integrated isiXhosa A-TAC version.

Owing to a lack of further time or funds, a further limitation to the A-TAC exists. Only the ‘first’ half, or gate questions, of each module were translated. These were prioritised as these would contribute in further research towards deriving cut-off scores. This does mean that half the items intended purely to develop clinician insight are missing. However, it can tentatively be asserted that the currently translated questions fill the same role.

With regards to the focus group, the age range and size of the group raises difficulties. In the original conception of the study, the Afrikaans group data was to be compounded with the isiXhosa data in analysis, resulting in twelve points of input. As only the isiXhosa group took place, this shrunk to six points of input. While this falls within the necessary range for a focus group (Terry et al., 2017), it would have been preferable to have more participants. Additionally, given that 5/6 participants were under age 35, it is possible that age acts as a moderating variable on the data. In such an instance, participant input may not necessarily speak to the perspectives or language forms of older generations.

In terms of my engagement with the data, another limitation is my overall English monolingualism. This is implicated both at the level of the group discussion and the analysis of transcript data. While it was important that the focus group be able to speak freely and comfortably in isiXhosa, this meant that I could not keep pace with discussion – even while live translating occurred through the MLS. For parts of the discussion that were in English, or otherwise where discussion was translated by the MLS Director, meaning was apparent. However, for parts of conversation that occurred too quickly for smooth translation, I missed

certain shifts in discussion. Thus, parts of the interview process, following along the interview schedule, became more directive towards certain themes than might otherwise have occurred if the groupwork had occurred in English. Additionally, I required the focus group transcript to be translated into English for analysis. This means that data was interpreted, not only through the lens of my own perspective, but also the translation lens of the MLS – rather than being interpreted in the source language.

6.4. RECOMMENDATIONS

6.4.1. Further adaptation of the A-TAC

- As discussed, half of the A-TAC has not undergone final adaptation. However, the initial translations exist. There is thus a need for further adaptation work to occur.
- Psychometric investigation should be invested into both translated versions of the A-TAC. This would include participant completion towards assessing inter-item reliability, as a starting point. Following this, the screen should undergo formal validation in order to derive cut-off scores for predictive use of the tool.

6.4.2. Healthcare research

- Language barriers and healthcare patients' sentiments of shame or denigration have arisen in research in SA and have been discussed. However, I did not come across references to *language shame* as a particularly emphasised theme in the literature. This raises a potentially new and interesting sphere for research.
- There is reason to believe that spirituality, bewitchment, and related elements, form an important explanatory model for Xhosa parents (both as indicated by the literature as well as one of the participants themselves). The theme of health detection accessibility would be bolstered by exploring how preference for alternative treatment methods would impact receptivity to NDD screening.
- The findings support current and future research investigating psychoeducative- and intervention-centred ECD programmes bolstering NDD support. Parents demonstrated a clear deference towards school-based detection, or detection support.

6.5. CHAPTER AND STUDY SUMMARY

In this study, I succeeded in addressing screen accessibility, from 1) the side of supplying a translated, deliberated version of the A-TAC screen. I further 2) unpacked isiXhosa parent

perceptions on the barriers to such health screening and the manner in which NDDs are conceptualised. Four themes of note arose.

1) Language barriers: a lack of isiXhosa in the clinics impeded effective discussion about the child, as well as results in embarrassment for parents for said lack of understanding. The need for effective translation modalities was raised. 2) Healthcare disillusionment: factors such as a lack of capacity or a lack of privacy lead to difficulties engaging with the healthcare systems. Parents indicated a desire to be the agents empowered to detect difficulties in the child. 3) Conceptions of child disabilities: NDD concerns would either not be spotted, would be explained as emotional turmoil within the child, would implicate poor learning or intellectual impairment, or would be caused by bewitchment. 4) Management routes opted for: parents may defer to inactivity. Of those that would manage the child, the routes included discipline, self-training, school support and healthcare centre attendance.

In SA, there are few translated, multi-domain NDD screens to draw on. The current study contributes towards alleviating this evident need. Additionally, few studies have investigated the perspectives of isiXhosa speaking parents in SA, who do not have an already NDD diagnosed child, with regards to their conceptualisations of NDDs. The abovementioned themes address conceptions of NDD cause, detection and management. The parents' discussion highlighted barriers to healthcare service and the need for additional support avenues, including within the school environment. A novel element to emerge was the experience of *language shame* in the public healthcare setting.

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APPENDIX A

LETTER TO EDUCATORS: RECRUITMENT ASSISTANCE

Multi-Lingua SCHOOL

English communication skills, tour and culture
General, academic, business and specialized
'Leadership and meaningful contributions through language'. Serving institutions, communities and individuals since 2005

Dear XX

REQUEST TO HELP US SEARCH FOR APPROPRIATE PARENTS WHO CAN BE PART OF A FOCUS GROUP

Mr Jacques Nel of the Neurodiversity Centre is currently busy with his M-Thesis through the University of Stellenbosch.

He would like to invite 6 parents for isiXhosa and 6 parents for Afrikaans to be a part of a FOCUS group to discuss a questionnaire regarding childhood developmental conditions, such as autism, learning difficulties, attention difficulties, behaviour difficulties, etc. The questionnaire was originally put together by the Department of Child and Adolescent Psychiatry of the University of Gothenberg, Sweden and recently translated for the Neurodiversity Centre (though Stellenbosch University) into isiXhosa and Afrikaans. However, Mr Nel and colleagues who will be using it, would like to assure that the translation uses natural Afrikaans and isiXhosa, is "colloquial" (spreektaal) and understandable, not necessarily the very formal or academic ways a translator would do it, and that parents will not unnecessarily be hindered by the formality or register of the language when answering the questions. Another goal is to make sure that the translated versions contain the exact same understood meaning as the English and Swedish versions. The idea is that the parents who partake in the focus group, help Mr. Nel to evaluate the questions in terms of their "naturalness" and what meaning is exactly understood for each question for people from all the different Afrikaans dialects (streekstaal) as well as in the case of the isiXhosa.

Following on this, Mr Nel would like to hold a group discussion with the parents, so that they can tell him about their usual experiences with these kinds of translated documents, what they understand to be existing issues with healthcare screening in their community, what they believe are factors that would hinder a parent's receptiveness or use of such as screen, and what their understanding of neurodevelopmental conditions are. Mr Nel would record this conversation, and then he would write about the themes and points that were brought up during the discussion. All parents would remain anonymous in the thesis, as he will only be discussing the themes and suggestions themselves.

The profile of the parents we are looking for is:

isiXhosa: 3 Male, 3 Female
A diverse age range would be appreciated.
Afrikaans: 3 Males, 3 Females
A diverse age range would be appreciated

The questions dealt with:

Coordination, concentration and attention, learning, memory, language, flexibility, nervous "tics", compulsions, eating habits, separation behaviour, behaviour and "uittarting", anxiety, mood, other, motor control, perception, planning and organizing tasks, social interaction, grasp of reality. Each of these topics have a few questions, in total 258 questions.

For the group discussion, we will address 1) what is the reception of the parents to this particular neurodevelopment questionnaire, 2) What is the nature/usual experience they have with healthcare documents they receive in the community, and 3) what is their understanding of neurodevelopmental conditions. Multi-lingua school will facilitate the sessions (either via Zoom or at the School), perhaps in May or June of 2021. The parents will be given the questionnaire and each of the above sections will be discussed and "evaluated" on for being "parent friendly", "colloquially acceptable" and the "specific meaning interpretation".

Participants of the groups will be compensated for their time and be provided taxi fare to the interview session. And at the same time we reaching out 2 or 3 educators in each community who would be able to help us identify possible parents for the focus groups. Although we would aim to have participants between the age range of 25 and 45, we welcome any interested participant so long as they are older than 18, and are a home language speaker of either Afrikaans or isiXhosa. We would also prefer that the participants not have close familiarity with child developmental /neurodevelopmental difficulties, as we would like them to give us their fresh perspective.

We will compensate you for your time R100 for every parent who joins the group.

We also attach to this email a flyer for parents. We would appreciate if you could please show, or email, the flyer to parents who may be interested. If they are interested, please ask them to:

- Contact the researcher, Mr Jacques Nel, with an sms to 076 998 1850, and he will be in touch with them.
- Or, with the parents permission or request, please give their phone number to Mr Jacques Nel so that he may contact them.

Thank you for your time and assistance

Helene Lambrechts

Founder & Director, Multi-Lingua School

RSC reg. no. 31300132472

Hélène Lambrechts - Language Facilitator MPhil.Linguistics

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Skype *easy.lingua* Multi-Lingua

APPENDIX B

STUDY ADVERTISEMENT FLYER

APPENDIX C

CONSENT FORM: ENGLISH & isiXHOSA VERSIONS

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Dear participant

My name is Jacques Nel, and along with the University of Stellenbosch I am completing a Masters Study called *'Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans'* [Ethics number: PSY-2021-22178].

You were told about this study through a teacher in the community, and agreed to meet with me today. I ask that you please read the information below, agree to take part in the study if you would like to, and give us permission to use any findings in the research paper. Please let me know if you need further explanation/details.

What am I being asked, and why?

There are two things that the study wants to achieve today:

1. We have got a questionnaire that checks for developmental issues or problems in kids (called the A-TAC). We got this English version from Europe, and translated it into your home language at Stellenbosch University. We would like to make sure that the translation makes sense and is worded properly in a way that sounds good to you.
    i. We ask that you agree to spend the morning helping us go over each item in the questionnaire, tell us if the item is good or not, & help us fix it if it is not good enough. If you are attending from home we will be covering your data. We will pay for your data. **We ask that you then allow us to record this session**.
2. We would like to have an interview with you. If we are together as a group, it will be a group discussion. The point of the group is that we would like to check 1) what your experience is with being given such translated forms, 2) what you think about the content of the forms and the conditions they describe, and 3) how you feel about this studies particular A-TAC measure. I will combine everyone's responses, and in the research paper I will talk about what themes, feelings and ideas came up.
    i. We ask you to agree to participate in such a group or individual interview, to allow us to record the interview, and to allow us to combine everyone's responses so that we can see what the main themes were.

The director of the Multi-Lingua School is helping me to do the group and translate discussions. She has signed a non-disclosure agreement, so any information that comes up in the group conversation will stay private.

Risks, benefits and compensation.

We will simply be collecting your views and perspective on different topics, including the language quality of our questionnaire. We will not be using your personal information, so **this study should be low risk for you** to participate in. It is possible you may get tired during the day, but we will provide a lunch break. With regards to benefits, the

study will likely not have direct benefit to you, but **you will be compensated R50 an hour** for your participation. This will be EFT'd directly to you.

What rights and privacy do I have if I take part?

Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. If you do withdraw, you will be compensated for the duration of the study that you took part in. Unfortunately, as all of the group work is conversation based, it is unlikely that we will be able to separate out your contributions and remove them if you withdraw. Thus any conversation up to the point of withdrawal will be included. However, we do not require any personal information from you other than mentioning age and gender.

You may withhold opinion if there is a sections of group discussion in which you would prefer not to take part.

Your personal information such as your name we will not be used in the study. We would only talk about 1) what all participant's ages and gender were, and 2) the input you give us for study questions.

- Any recordings we make will remain securely stored on the Stellenbosch University server. I will control access to this recording during the period of writing down the conversation.
- Any paper information about the interviews will be securely stored in the Stellenbosch Department of Psychology, in a locked cabinet in the office of the supervisor.
- The language facilitator helping me, from the Multi-Lingua School, will be held to a confidentiality agreement. She will have access to the data while we work on it, after which point it will be closed to her.
- In the research paper, we will use a fake name rather than your own. Your name will not be used at any point during the writing of the paper.
- The anonymous data would be used in the research, published in an academic journal, and the written version of the focus group discussion shared to a secure journal repository, which would need special ethical permission to access. This will be completely anonymous and cannot be back-tracked to you.

RIGHTS OF RESEARCH PARTICIPANTS: You may withdraw your consent at any time and discontinue participation without consequence. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development. You have right to receive a copy of the Information and Consent form.

If you have any questions or concerns about the research, please feel free to contact Jacques Nel (researcher) at 076 998 1850 // jacques327nel@gmail.com, or Dr Zuhayr Kafaar (supervisor) at zkafaar@sun.ac.za.

DECLARATION BY PARTICIPANT

By signing below, I …….. agree to take part in a research study being done by Jacques Nel called `*'Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans*, and allow research to be used in the study and anonymously published in academic journals.

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** & I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

- All issues related to privacy and the confidentiality and use of the information I provide have been explained to my satisfaction.

Signed on (date): …… **Signature of participant……..**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to the participating group members. *They were* encouraged and given ample time to ask me and my language facilitator any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa*] and their conversation was translated into *English* for my own sake by the Multi-Lingua Language School.

_____ _____

Signature of Investigator **Date**

IYUNIVESITHI YASESTELLENBOSCH

IMVUWE YOKUTHATHA INXAXHEBA KUFUNDO BANZI

Mthathi-nxaxheba obekekileyo

Igama lam nguJacques Nel, kunye neYunivesithi YaseStellenbosch ndigqibezela iMasters Study ekuthiwa "Translating the Autism-Tics,ADHD & other comorbidities'[A-TAC] inventory into isiXhosa and Afrikkaans' [Ethics number:PSY-2021-22178].

Uxelelwe ngolufundo ngutitshala wasekuhlaleni,kwaye uvumile ukudibana nam namhlanje. Ndicela ufunde ezincukacha zingezantsi,uvumele ukuthatha inxaxheba ukuba ufuna njalo,usinike imvume yokusebenzisa iimbono zakho kolufundobanzi. Ndicela undazise ukuba ufuna enye ingcazelo.

Ndibuzwa ntoni,kwaye ngoba?

Zimbini izinto ezifunwa lolufundo namhlanje:

1. Sinemibuzo ejongene nokukhula kwabantwana kunye neengxaki zabo (ibizwa iA-TAC). Siyifumene e-Europe,ibhalwe ngesiNgesi,sayitolikela elwimini lakho eYunivesithi yaseStellenbosch. Singathanda usincedise sijonge ukuba itolikwe ngendlela eyenza umdla okanye evakalyo kuwe.
    i. Sicela uvumele ukucitha intsasa yakho usincedisa ngokujonga umbuzo ngamnye,usixelele ukuba ilungile na,usincedise ngokulungisa ezingingalunganga. Ukuba uzakusincedisa uhleli endlini,sizakunceda ngedata. Sizakuthengela. **Sicela imvume yokurekhoda.**
2. Sicela ukuba nodliwano-ndlebe nawe. Ukuba nidibene ibeyingxoxo. Injongo yengxoxo kukuba 1) sijonge amava onawo ekuphenduleni iform ezinjenga lena,2) ucinga ntoni ngengxelo yaleform kunye neemeko ezibonisayo kwaye 3) uziva njani ngolufundo lweA-TAC. Ndizookudibanisa zonke iimpendulo kufundo banzi ndichaze zonke izimvo kunye nezicinga ezivelayo.
    i. Sicela imvume yakho ukuze sikwazi ukurekhoda udliwano-ndlebe,usivumele sidibanise zonke iimpendulo ukuze sijonge umxholo.

Umlawuli weMulti-Lingua School uzakundincedisa uudibanisa nokutolika iingxoxo. Utyikitye isivumelwano sokungavezi,kwaye yonke into ethethwayo izohlala ifihlakele.

Umngcipheko,izibonelelyo kunye nembuyekezo

Sizakube sijongene neembono zenu kwimiba eyahlukileyo, ngakumbi elwimini elisemibuzweni. Asizukuzisebenzisa iincukacha zakho,olufundo alisukufaka mngciphekweni. Kungenzeka uzive udiniwe ebudeni bemini,kodwa sizokuninika ixesha lukuphumla. Ngembuyekezo, ufundo banzi lungangabina mbuyekezo kuwe kodwa **uzoknikwa iR50 ngeyure** ngokuthatha inxaxheba. Sizakuyithumela ngeEFT kuwe.

Ndinawaphi amalungelo nokhuseleko ukuba ndithatha inxaxheba?

Ukuthatha kwakho inxaxheba **kuxhomekeke kuwe** kwaye uvumelekile ukuthi awufuni. Ukuba awufuni,ayizoku nika igama elibi lonto nangeyiphi na indlela. Uyakwazi nokuphuma phakathi elufundweni,nokuba ubuvumile. Ukuba uphume phakathi,sizakubhatalela ixesha olichithileyo elufundweni. Ngelishwa,kuba umsebenzi uncokolwa,asizokukwazi ukukhupha iimbono zakho xa wena uthe wayeka phakathi. Zonke iimbono zizakufakwa. Kodwa asifuni zincukacha zakho ezininzi,nje iminyaka kunye nesini. Ungathula xa kukho indawo engxoxweni oziva ingathi awufuni ukuthetha kuyo.

Iincukuca zakho ezinje ngegama azizokusebenza kufundo. Sizakuthetha ngeminyaka kunye nesini somntu othatha inxaxheba kunye neembono zodwa.

- Sizakugcina zonke iirhekhodi ngokukhuselekileyo kwiserver yeYunivesithi yaseStellenbosch. Ndizakulawula ukufikeleleka kwerekhodi xa kufuneka ibhaliwe.
- Onke amaphepha anento enokwenza malunga nodliwano-ndlebe azakucinwa ngokukhuselekileyo eYunivesithi yaseStellenboch kwicandelo le Psychology,ekhabhathini etixiweyo yomphathi.
- Umququzeli wolwimi ondincedisayo waseMulti-Lingua school,uzokuhlala esivumelwaneni. Uzakufumana ixesha lokujongana nolufundo,emva koko angaphinde alufumane.
- Koluphando, asizokusebenzisa igama lakho lokwenyani.
- Ezincukacha zilapha kouluphando, zizakushicilelwa kwijenali yofundo, elicala libhaliweyo lifakwe kwi (Journal repository) ekhuselekileyo. Igama lakho lizakuhlala lefihlakele kwaye ayinakubuyiselwa kuwe.

AMALUNGELO OMTAHTHI-NXAXHEBA: Ungayeka phakathi ekuthatheni inxaxheba ngaphandle kweziphumo. Awuzungena ngxakini kunye neenkundla zamtyala ngenxa yokuthatha inxaxeba koluphando. Ukuba unemibuzo okanye ufuna ezinye iincukacha,tehtha kunye no Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development. You have right to receive a copy of the Information and Consent form.

Ukuba unemibuzo okanye iinkxalabo ezimalunga nolu phando, ukhululekile ukuba ungaqhagamshelana noMnu. J Nel (umphandi) ku-076 998 1850 // ku-jacques327nel@gmail.com, okanye uGqr. Z. Kafaar (owongameleyo) ku-zkafaar@sun.ac.za

DECLARATION BY PARTICIPANT

Ngokutyikitya apha ngezentsi, Mna ..... Ndiyavuma ukuthatha inxaxheba kuphononongo lophando olwenziwe nguJacques Nel ebizwa ngokuba `*Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans*, kwaye ndivumela uphando ukuba lusetyenziswe kwisifundo kwaye lupapashwe ngokungaziwa kwiijenali zemfundo.

Ndifunga ukuba:

- Ndiyifundile incgazelo yonke,kwaye ibhalwe ngelwimi endilkwaziyo ukulifunda nendiqinisekleyo ngalo.
- Ndinikiwe ixesha lokubuza yonke imibuzo ebendifuna ukuyibuza,ngaphendulwa.
- Ndiyaqonda ukuba ukuthatha inxaxheba kuxhomekeke kum .Andinyanzeliswanga.
- Ndingaphuma nananini ndifuna koluphando,andizokufumana xinzelelo.
- Ndingacelwa ndiluyeke uphando nanini na ukuba umphandi uva ingathi ndifanele oko okanye andenzi nje ngesivumelwano.
- Zonke izikhalazo ezidibanise neencukacha zomntu nokusebenziswa kwazo ndizicaciselwe ngokwaneleyo.

Signed on (date): ..... **Signature of participant.....**

APPENDIX D
INTERVIEW SCHEDULE

Content to be translated verbally during group sessions by the Multi-Lingua School. The focus group will be handled flexibly, and if certain questions are answered in the course of discussion, follow-up questions may be presented differently or not at all if no longer relevant.

Questioning the Measure Itself

This document was already translated at the University of Stellenbosch. We have worked together today to look through it and adjust it.

1. *How do you feel about the new version of the screen*? [Explain?]
2. *Let's talk about the difference between the original translated version and the new one*.
    a. Follow-up: *Would you want this form to be presented in English, in Afrikaans/isiXhosa, or both*? [Why?]
        i. Follow-up (if not yet addressed): *Are you usually more comfortable receiving forms in any specific language*? [What? Why?]
        ii. If English is preferred: *Would you first look at a translated form to see if you are comfortable with it, or would you go straight for an English form*?

Accessibility of Translated Documents

Many organizations translate documents like this. You may see form, letters or pamphlets like these as well, such as at schools or hospitals. These forms try to ask you questions or give you information.

1. *Do you see similar translation issues in such documents*? [What?]
2. *What should be done when people are translating documents*?
3. *Do you feel groups like this are a good idea for translating documents*?

a. *Do you feel that a parent would be able to answer a form like this alone, or only with the assisted reading and explanation of a healthcare professional*? [Does this change depending on the language presented?]

Neurodevelopmental Measures

We have looked a lot at the meaning of different questions today.

1. *Do any of these questions or what they describe sound familiar to you? Do you know children that sound like this?*
2. *What is your understanding of children who sound like this? What would you think is the reason or the cause?*
3. *If your child matched some of these descriptions, what would you yourself do?*
    a. Follow-up: *If the child matched descriptions on this form, who would you want to read this form in order to give you hel*p?
4. *What is your understanding of developmental issues (meaning children who are born with difficulties)?*
    a. *Do you know autism*? [Tell me about it,]
    b. *Do you know ADHD*? [Tell me about it.]
    c. Test question to distinguish psychosocial from neurodevelopmental understanding: *Do you know depression*? [Tell me about it.]

APPENDIX E

TRANSCRIPTION

Multi-Lingua SCHOOL

English communication skills, tour and culture

General, academic, business and specialized

'Leadership and meaningful contributions through language'. Serving institutions, communities and individuals since 2005

KEY:	
[words]	Overlapping speech or contextual descriptions
…	Pause taken
(…….)	Portion of transcript excluded (for non-study-related content, such as set-up or technical difficulties)
(description)	Provides additional behaviours such as laughter
{words}	English translation for isiXhosa phrases
-	Sentence cut-off or revised half-way through
“ “	Participant is phrasing a hypothetical sentence or scenario

Researcher: Jacques (Jac)
Multi-Lingua Director (MLD)
Participant 1 (P1)
Participant 2 (P2)
Participant 3 (P3)
Participant 4 (P4)
Participant 5 (P5)
Participant 6 (P6)

Please note that participants speaking in direct interaction with one another, rather than simply raising their own independent points, are presented below in the same block as one interactional whole.

	0:00	(…….)
Jac	2:32	Okay, fantastic. So, you are welcome to speak, um, in Xhosa. We are recording so that we can - [group laughter] - actually write it down and translate it later on, um, for the study. You are welcome to speak in Xhosa and Helene will help me. I just want to start by getting an idea of how you found today's questionnaire? What do you think of the version we are currently working with?
MLD	3:13	Think about it, you are now already a parent, I would say, think about it and you are at a clinic, and they give this questionnaire to you, how would you feel about it - how do you rate it, yeah?
P3	3:41	Uhm, I think as I stated outside, that the questions are very good - for everyone. They are so understandable, and we as - I think we as parents **…** I think its gonna work for everyone, even for the ones that - the one's that didn't go to school, they can understand the questions.
	4:14	(…….)
Jac	4:43	Okay, and - thank you *P3*. And how would the rest of you feel, would you agree? [murmurs of agreement]
P6	5:05	I agree with *P3*, it is just that that a few words that need to be change, which I am not happy about and are hard read and be understood, other than that, it's fine.
P5	5:33	- Can I add something also guys, too? [A participant murmurs agreement] Yaa ne, if you go ekliniki {the clinic} sometimes and you meet inesi {nurse} even if that nurse is coming from a school or **…** at clinic, most medicine is not written in isiXhosa, our parents only know iDisprin, Grandpa, and Panado for headaches, so other medicines that are - that can

		be used to, to cure other illnesses that is happening, with children around the home, we don't know anything about that.
Jac	6:18	So would you say … no one really give information … to parents?
P5	6:30	No, what I am trying to say - some of us ne, we are coming to areas where we speak our native language isiXhosa. Now when you come here ekliniki {the clinic} you find a doctor - she's a Indian, or a young white or a young coloured lady. Obviously, she won't be able to speak your language or understand you. So sometimes there's no space for our parents to - for someone to explain to them.
P3	7:01	Ooh, languages. [P4: It's a problem of languages, where they can understand.]
MLD	7:07	Is that why a questionnaire is good … it is a problem of the language? [technical difficulties with audio begin]
		(…….)
Jac	8:21	If you go to a health care centre, do you usually have these documents translated for you? [P5: Hayi {No}] [P3: No]
P4	8:39	For example, our parents used to go to another doctor, like kwaStelkor, that guy, he does not [Another participant: hmm] speak isiXhosa, but he knows our parents. He will give them the medication. And they will pay and no one is going to say "mama, you see this, this medicines is for this and this, and this is the side effects" - no they don't do that. They will tell "Okay mother, I'm gonna give you this and then I am gonna give you an injection." No one is explaining anything to them.
Jac	9:12	Okay. [MLD: Is that what generally happens?] [P4: Yes] [A lot of noise]
P1:	9:29	If some point, in going to healthcare centre, when like - maybe if the person - when like maybe a patient has a language barrier, and then if the person akakwazi ukuthetha {he can't talk} English ne, and then ugqirha akakwazi [audio disrupts over this portion of the sentence] akamva uba uthe unantoni. {They can't hear what they say is wrong with them} [P4: Exactly]
	10:07	(…….)
Jac	12:51	Uhmmm, if I am correct, there should not be an echo now. Am I - okay … so, okay - we may have to back track somewhat (chuckles). We were saying that there is no Xhosa resources, um, at the healthcare centres, parents do not get any explanation in a language they understand. Would anyone like to speak a bit further on that? You can also speak in Xhosa.
P5	14:01	Ah, kwi-public clinics, zethu, it not the same like the private sector, or Medi-cliniki - soloko kucwele {it is always full} all the time ne, and sometimes as a parent, it's not easy to speak out or - uzama uku-explaina kukho abanye abantu,{you are trying to explain and there are other people} find ukuba umdala {you are old} and the person who is attending you, umntu {person} maybe she is 26, 27. Noba ichallenge esinayo.{maybe that's the challenge}. Uyabona?{you see} [Another participant: Yebo {Yes}] And sometimes you find buthi {brother [addressing Jac]} at ikliniki they do give you iPamhlet {the pamphlet}, "read this, read this" - yeah you can read something but as a parent you don't understand what does it mean - uyabona? {you follow?} and the person who is gonna ask will

		say "Eeh sis, do you understand this?" and sometimes she is asking you and there are other people around you - [P2: Ehh [agreement]] - and you're gonna say "Ewe, I understand" not - andifuni ukulook like "dom" (I don't want to look dumb), okanye - uyabona.{you see}? That is another challenge we have at the kliniki.
P1	15:19	Okay, I think mna {myself}, another thing is I that - xa uye kwihealth facility ne {when you go to a health care facility} like most - some of the ii-staff nurse okanye oonurse abasebenza kuloo kliniki uye kuyo {or the nurses that work in that particular clinic}, xa kukho umzali onenxaki mhlawumbi yelangauge, fanele ukhona umntu oncedayo ukutranslate {when there is a parent who has a problem with language, maybe there should be someone to help them translate}. - but, abanye abantu, sometimes, baye bafumanise xa ubuza ukuba ebesithi la gqirha, afuna ukushow-offa ngawe [end of sentence missing] {other people realise that when you ask what the doctor said, they tend to make a show-off [spectacle] of you}. [P5: Exactly, stigmatized!] Umntu akubuze kutheni ungayazi iEnglish umdala kangaka {You find them asking you why you don't know English at this age} so ke ngoku umntu asuke nawe kwiConsultation room aye ma naye kwiCorridor - afune embarrasa in front of everyone of which nawe ikwenza ufeele stupid {so now they will take you from the consultation room into the corridor just so they can embarrass you in front of everyone and make you feel stupid}. [P3: "How come we don't understand this?"] Awuyazi iEnglish, mhlawumbi awuyazi iAfrikaans, ufeele ustupid as umntu {You don't know English, maybe you don't know Afrikaans, you feel stupid as a person}
Jac	16:39	So, would you say the parents get treated like a bad parent just because they aren't given the time or the translated material or the proper explanation?
P1	16:57	Yeah, yes I can say so because you know maybe - if umntwana wakho onedisability mhlawumbi une-autism okanye okany uyathinthitha okanye mhlawumbi noba yeyiphi idisability anayo if so ke ngoku {if the child has a disability, maybe autism or they stutter or maybe another disability they have}, I think xa umntanakho xa exelelwe kugqirha umntwana unedisabilitiy - I think the responsibility as a parent yakho funeke wenze is to research about idisability yomtnwana wakho {when the doctor says the child has a disability, I think it is the responsibility of the parent that they need to research the child's disability}. If mhlawumbi uye ekliniki oko koko or esibhedlele oko funeke ubuze engoku into yoba xa ethe mhlawumbi uyaxhuzula or unefits ubuze angancedwa yintoni or umthini umonitorishe kanjani {If you perhaps go to the clinic or hospital, you need to ask what is happening, if he is maybe having fits or seizures – and how you need to help or monitor him}. But ke ngoku nalapho ilanguage iyabetha because awuyazi uzothi ukuxhuzula yintoni ngeEnglish {But even so the language is then a struggle because you don't even know what the word for an "epileptic seizure" is in English}. [P5: (laughs) "shaky shaky, jumps"] [Another participant: Epilepsy] [Another participant: Yeah] Loo nto iyiyo {It is what it is}. It's just that i-Language is very important. Mmm, but mna {myself} I don't see any reason why people must be ashamed of ihomelanguage zabo {of their own home language}. If you don't understand into ngelanguage yakhe {something in their language}, you have a right to ask. Whether umntu uyakuphoxa or akakuphoxi {whether they correct you or not}. It is your right to ask, so that you can understand.
Jac	18:59	Sorry if I am a bit delayed. Helene is translating for me as we go (chuckles). … Um, thank you. I think you brought up a lot of really strong points there, the stigma, the fact that parents get made to feel ashamed. and that you should be treated well in your own language. Do you think a screening form like this, if it was given at a health care centre, that parents should answer it alone or should it be with a staff-member who helps parents go through a form like this?

P4	19:56	I think it would be much easier if it can be at the centre whereby if someone doesn't understand the question, they can ask the person sitting next to them "what is this question, can you explain this question to me?"
P1	20:14	Okay, to add to that, mna {myself} on my own - I think if the parents and the health care workers can be put together and sort of like having a debate, so that ii-parents they can raise their concerns about the healthcare workers. Uyabona {you see}? Because they have to be patient with abantu {people} with language problems, because it is not a sin, ingqondo zethu azifunkshini ngofanayo. {our thinking does not match/function in the same way}. Funeke babe aware of abantu abazi kwiklinics ba-eperienca ntoni, bayazi. {They should be aware of what people experience in the clinics, they should know}.
P2	21:02	Ke ngoku, I also think awukwazi ukuba ustigmatizwe yento ongakange uyenze {And then, I also think you can't be stigmatised for something you haven't done}. So, the health care worker and, uh, the parent have to find i-understanding yokokuba {which is} the reason why we silapha ka lomntwana {we are here for this child}, funeke kubekho, andiyazi, i-middle ground {there must be, I don't know, some middle ground} - this is not our fault, this is not anyone's fault, but we just need to help the child navigate through life with whatever they have as a challenge.
P3	21:46	I think we need more people like, at the clinics, more people like social workers, someone who can be there for abantu {people}. [P2: Mmm, yeah] Umntu ozoyazi ukuba "luxanduva lwam lo'kuba manditranslate this ebantwini" {A person that knows that "this is my responsibility to get across to people"}. Not umntu ozosuka, mhlawumbi edesikeni yakhe athi uba {Not someone who is going to leave, is maybe inside at a desk and tells you} "I have a patient inside" **…** somebody standing on that platform, uba "I am translating for people, people need to understand this, if kukhona into abangayiqondiyo {there is something they don't understand}, I am the one they should consult, not anyone else." I think we need loo nto {that} in our clinics, makubekho lamntu oyi-one obekiweyo phana ifriend uba uyazi uba {let there be a designated individual who is the translator} - this is the person who is going to translate the language to people. This is the person we call when someone does not understand the language. [P1: Another thing-] [P4: Yes, to add-] [MLD: So, we are hearing … it would be wonderful to have a health language consultant at the clinic?] Yes, yes, yes
P5	23:08	Even if not inside the clinic, maybe a container outside - maybe there is going to be two or three people who are sitting there. Because if someone is going to a clinic ne, and go inside and then explain, there is going to be no space because majority of people are going inside. They need attendance of a doctor. So, I think that should be done outside - in the same vicinity, but not inside. If umntu ufumene imedicine or i-injection {if a person gets medicine or an injection}, wahamba engakhange a-understande kakuhle {they leave without a good understanding} what the doctor said - [P1: Eeh [confirmation]] [P3: Yeah] - or a-understande ipilise zenza ntoni {or what the pills are for} so that it will be easy for someone angaphindeli back eklinik, aye kula container {not to go back to the clinic, but go to the container}. Because, another thing, going back to the clinic, is not easy, awuzo fika kukho abantu aba-yi-ten {you will not be first there, will be at least 10 people}.Hayi, uzofika, kukho {No, you come and there are} other people and it is it is full eklinik {at the clinic}, inside and outside, people are watching you, like there is something wrong with you. Singabanye asifani {We are each different}. Abanye bethu ba-sensitive {Some of us are sensitive}. So maybe if - because the University of Stellenbosch mos, inemedical students ezenza itheory abanye benza ipractical, so maybe if ungabakho icourse, maybe for 6 months kubekhona itraining kwenziwe ibasic understanding yezinto ezenzeka ekliniki {because the University of Stellenbosch has medical

		students who are doing theory and practical, maybe you have a course for 6 months providing basic training on dynamics at the clinics}. Then ingalula njalo {then things will be easier}.
P6	24.40	Unyanisile {you are correct}, because sometimes ugqirha uzobane-excuse ubane-explaina to loo mntu {the doctor will have excuses they give to the person} because thina singabantu mos sinestyles - sindiniwe uyakwazi ukuthi hayi, ndinepatient andizomncedi lowa {They will not explain to the people, and will just say they are tired and that, no, they have other patients and so cannot help}. [P3: "I have a lot of queue outside", yeah] [P5: Yeees]
MLD	24:58	So, there is that pressure that "I cannot really, really tell you how to take care of your sickness or how to take care of yourself or your family member, because I've got this line behind me that's pushing me all time". [P6: Exactly] [P4: Yeah]
Jac	25:20	And do you think these issues about privacy and business are made worse when it is about your child? [P3: can you repeat your question?] Do you think the need for privacy is more when it is about your child, because people are looking at how it reflects on you as a parents? [P3: Definitely] [P1: Yeah] [P2: So so much]
P2	25:57	Our children made to feel bad about themselves for things that they did not do to themselves, uyabo {you see?}. They are made to feel bad for us giving birth to them. So, this would be another one **…** eyenze kaworse {it is made worse}, because eklinik oones bayakwazi ukwenza umntwana azive as so small {in the clinics, they can make the child feel so small}.
P3	26:22	And it is not only for children as well, it's also big people as well - like sometimes at the clinics, they make you end up feeling like - like for instance some other people they don't like to come to [NAME] clinic, they prefer to go to Dal, because the situation at [NAME] clinic is worse (repeated X4) than the other clinics.
MLD	26:43	Is that privacy issues?
P3	26:48	Mostly yes, so it is like maybe they feel like - some patients feel like "Yho, maybe I have chosen to be HIV or I have chosen to be sick", you know? [MLD: Hmm]
P1	27:09	Okay, to add on what you are saying with *P3* ne, you see *MLD*, here in [COMMUNITY] there are people who know when your name is being called on Room 9, you are going to take chronic for HIV so when you are being called on room 5, you are going to take i-treatment for TB. [MLD: So, the room has a certain stigma?] [Everyone: Yes!!] [P1: That is why people no longer feeling safe to use this clinic] [P3: Because it is not private anymore, everybody knows]
P4	27:49	Because I don't go to room Room 1 anymore eklinik {at the clinic} because I know Room 1 is for men's clinic. I don't go there. [Participants laugh] [MLD: I was wondering which is the "Umqhombothi" room] [Participants laugh]
P5	28:17	You - now you see *MLD*, there are many challenges there for us youth, for young women who are mothers now, and for young girls who are not mothers who need i-attendance not just coming to the clinic because they are sick, no hay- ah, [P2: i-family planning for the kids as well]

		[P5: Exactly] Because in our community, we don't have social workers or i-centers where they will teach children about safe sex, pregnancy and how to prevent - no. That thing is only happening at school, maybe for an hour or two, but that doesn't mean as a child you are going to know what you are going to need to know. No, remember you are a child and your brain is still developing so that's other challenges esinazo {we have}. So, we need people from eyunivesathi Stellenbosch otraine abantu bazokwenza ezi zinto {from the University of Stellenbosch to train people to do these things}, Not workshops. Nale workshpob eibe on a Saturday not everyone is going to be there, uyabo {you see}, on a full-time basis, uyabona {you follow?}
MLD	29:28	Okay, let us pull it a bit back and go to ukukhula kwabantwana {child development} - development of children specifically.
Jac	29:46	So, um, I just want to get the sense of, for all the questions we went through today - all those sentences on the questionnaire. How familiar they sound - can you think of children like that and what would people - what would parents, in general, think of the children? What is the normal idea of what this means when they look like this? [P1: (laughing)]
P3	30:17	I think for us as parents, first of all we have to observe on our children. You know? Some other kids bane- they are having a -a lack of learning, they are having a lack of speaking, they having i-lack of behaviour and moving and all of that. So, I think for us as parents, it is our job uba si observe,abantwana bethu, and then sijonge ukuba ingxaki yom umntwana wam iphi ne, and what do I as a parent do if umntwana wam unenxaki ethile? Uyabo? {It is our job to observe our kids and to look what the child's problems are, and what do I as a parent do if my child has struggles? You see?}. And I am the one if ndiyabona uba {I can see that} maybe my child has a problem, I'm the one who needs to go to school to address the problem of my child. Uyabo {you see}? It is a private thing, but then still, umnt'nam uye pha for ufunda so umiss womntwana {my child is here to learn so the teacher} has to understand what is happening to my child.
P1	31:16	Okay ne, ndiyakuva ne {I understand}. Like, iChild development, mna {myself}, I think the first person who notices if there is something wrong about the child is the parent, because when umntwana ukhula {when the child grows up}, you start to notice that there are abnormal things angazenziyo, enzingafani nabanye abantwana {they do, that other children do not}, - [P3: Yeah] mhlawumbi omnye sislow learner, omnye akadlali nabanye abantwana, okanye ibikhona nje into ngomntwana wakho {maybe one is a slow learner, or another is not playing with other kids, or there is just something that isn't right about the child}. Now if wena [a portion of audio is distorted] **…** I think it is your responsibility to tell the doctor about uba "I have noticed this and this and that about my child". "Ingaba mhlawumbi unesifo okanye unedisiability?" {"Do they maybe have some disease or disability?"}, because sometimes it happens **…** Uzale umntwana enormal but xa esithi 1, 2, 3, ubone no maan, there is … something wrong umntwna wam {You give birth to a normal child, but when they get to age 3, you start to notice, there is … something wrong with my child}. [P4: Hmmm [agreement]] And then ke ngoku, into ibe uyeke umntwana akhule. Then ke if ugqirha ubuyele kuwe, wathi no, umntwana akakwazi ukuthetha kakuhle, funeke udibanise nespeeck therapist **…** then wena ke ngoku umzali it is your responsibility to know uba ispeach therapist sisomnceda njani {And then you let the child grow up. Then maybe the doctor gives you feedback that the child has speech problems and refers you to consult with a speech therapist **…** then it is your responsibility now as the parent to understand how speech therapy is going to help}. Idevelopment yomntwana izokwenzeka nyani. Ube aware and iunderstanda and if umzali uyaiundaerstanda isituation yomtwana wakho, uyayazi indlela ukumnceda {Be aware and understand, and if the parent understands the child's situation, then they know how to help}. And na xa uzoaplyela isikolo, ne, I think paya kwiapplication form ikhona indawo ethathayo uba umntwana unayo isickness or unayo idispibility, so that if esikolweni mhlabi uyanceda

		ujongwa, hlwmbi ununmntana ofuna {And when you go to the school, I think indicate that your child has a disability on the school forms, so that the school can maybe help and watch the child}. Ujongwa yonke into ayenzayo funeke ejongiwe, yaziwe {You need to watch and be cognisant of everything he does}. Not uba ungumzali kuthiwa umntana wenze into ethile esikolweni, upretende ngathi awuyazi kodwa uyayazi {Not that when the child does something at school, you act like you don't know when you actually follow what happened} .
Jac	34:18	Thank you, *MLD* is still translating for me **…** Who put up their hand?
P6	35:46	So, uba ndiyeva kakuhle le question ithi, sifila kanjani ngale questionnaire, or kangnakani entweni esizibonayo {if I understand the questions, you are asking how we feel about the questionnaire and how it relates to our real-life situation}. So, phot mna kwelam icala, aphe eskolweni, ndizokwenza umzekelo ngento enzeka aphaka kunalomntwana ufunda ugrade 1, unale ngxaki yoba if ukhe wabethwa okanye wadlala elangeni, kakhulu fumniseke xa ebuy eklsini akekho right akamameli, okanye uneeesound ufunny, or mhlambi udumbile. {So, from my side, I will make an example of something that happened to a Gr 1 child. He has this problem where if he plays outside in the sun, when he returns to class he is not the same, he makes funny sounds and he looks swollen}. So sometimes - in fact ngenye imini sakhe sabiza abantu wabe esithso no mama'khe esithi nasezibhedlele into yakhe ithini. {one day [the school] called some people and the mother confirmed that the child has had to see doctors before because of this behaviour}. But xa sibiza abantu ba external, babe besithi lomntana okananix, lomntana fanele abe kwi mainstream schooling, but to come back to kule part ye barrier, kwilanguage, ndiye nakwi part ye lack of information {But when [the school] called external people they said nothing was wrong with the child and that he should be in mainstream school, but maybe it was because of a language barrier and a lack of information}. Nantso nje ipart endifuna uyacheza and ndiconfrme be yonke lento iyenzeka {That's what I wanted to say and confirm that all this happens, also at school}.
P2	36:25	Okay, so bendizophendula nam kulanto ibithethwan ngu*P3* no*P1* {I was going to add to what *P3* and *P1* were saying}. Most of the time umntwana ubonwa nyan nyan {the child is truly seen} 1st by the parent and then the parent decides whether, yena - if the parents puts on a stigma on what is going with the child, the child then xa emphumayo {when they go out} - kuqala iqala apha endlini {it starts in the home}. If the child is treated like something is wrong. Uyabo {you see}? It stems from there. Ingxaki {the problem is} we are most if the time - si {we are} -ill-informed about things like i-autism. In the questionnaire [portion of audio missing] **…** we never find people who ask us the questions that are asked **…** [Jac: Thank you so much *P2*, and did you cut out?] Sorry, I wasn't done, I just lost myself, sorry. If we had people that asked these questions when you have a child initially, because most of the time nawe as the parent you are in denial in your mind and awufuni ukucinga {you don't want to think} that your child is special. You don't want that. So, most of the time it would be great if there was someone who was asking these questions xa ubona uba ikhona into ewrong ngomntwana {when you see there is something wrong with the child}. Thanks, I'm done.
Jac	38:40	*P3?* Your hand is up? And your mute is on. [Group laughter]
P3	38:59	Yoh guys, I think there was a question, I'm still looking for it here on the questionnaire (pages flipping) **…** Okay, the - it's the last page T91 Oh, okay ithi ba la question, "Ingaba wayekhe wazichamela emini amatyeli aliqela emva kweminyaka emi-5?" ne? [Original T91 English: {Has he/she wet him/herself during daytime on several occasions after the age of 5?}] [Garbled audio from other participants]

	40:12	(…….)
Jac	40:28	Yes, are you asking about the, um, questionnaire T? [P3: Yes T … 91]
P3	40:41	Yes, I don't know if ndiyiva wrong na le question, ithi ingaba umntwana wakhe wazichamela after 5? {I don't know if I am hearing this correctly, is it asking if the child ever wet the bed after age 5?} [MLD: Does he wet himself after 5?] Like 5 years? [P4: Yes] [Jac: Yes, yes after age 5] Cause I think thina singabantu neh {because we are people, right?}, we, we, … Thina singabazali siyathanda ubetha abantwana xa bechamile bengena 5 {we as parents like to give our child a smack when they wet the bed even before they are age 5}, not knowing ba yingxakileyo {that they are troubled} so bendicela ukubuza kengoku ingaba yingxaki leyo na {so I am asking if that is an issue}?
Jac	40:59	So, would you say, a lot of these questions get treated more as a behavior issue to be punished? [P3: Yes] How much-
P5	41:50	-can I add something ku*P3*? Ya, because ekhaya ne, kukho umntwana oyinkwenkwe ona-8years {at home there we have an 8-year-old boy}, he likes playing with his friends. His friends are older than him, they bully him and he likes playing with them. They always fight all the time, but we notice ukuthi sometimes uyachama xa elele {he sometimes urinates while sleeping}. Then one day mamkhe wabona uba za elele ingathi uyaphupha ngathi ukwiplay ground. Aphinde athi umamakhe lomntana udreama what was happening kuye kule bullying bayenzayo, because uyabullyisha abancinci naye uyabullishwa {Then one day, his mother saw that when he is asleep he seems to be in the playground, then his mother also says he could be dreaming about what was happening to him because he is bullied. He also bullies others}. Uyathanda ukudlala nabantwana abadala {He likes to play with older children}. I think yenye ingxaki for abantwana {that is another problem for children} because bullying that is happening at school, after school. Sometimes you find umntwana akakwazi ukuyireporta lonto ebazalini because uyoyika {the child cannot report what happens to parents because he is scared}. So, I think nalonto ibane effect xa elele, athi xa edreama udreama ngalanto ibisenzeka {this has an impact when he sleeps, and he dreams about what is happening}. That is my view. [P3: Okay]
Jac	43:18	So, if you … saw a lot of these concerns in a child, where with the behaviour issues, where they don't concentrate, or they're impulsive or make weird sounds, what would be your first go to solution?
P3	43:50	I think I would firstly go to the teacher, find out how is the child in the class. [P5: Ya] And then from there mos, most of the schools, maybe they have psychologists and all that, then I will ask them to help the child. [P6: Yeah] … Then if maybe they can't, then that is when you go to the social worker to try and find help.
P2	44:36	I wanted to say that, first I would try and find out - or maybe try and figure out when the behaviour started, or maybe try and recall a time when the child got some traumatic experience that maybe made the child develop things. Because sometimes siye sibe oblivious kwizinto ezenzeka ebantwaneni bethu {we can be oblivious to what has happened to our children}. Kuba imini yakho ingakhange ihambe kakuhle ungacingi ubuza uba "how did this happen?" or "ibinjani imini yakho?", {Because you had not had a good day, you do not think to ask "how did this happen?" or "how was your day?"}, "what kind of experiences did you have namhlanje {today}?", so that you try and collect information because ezinye izinto zenziwa yitrauma

		ezinqgondweni zaboand then after la trauma umntu angaphinde abuyele ekubeni nguye{because some things are caused by trauma in their mind, then after the trauma they cannot return to being themselves}. [Group murmurs of agreement] So sometimes the things that happen ebantwaneni bethu siye sizithathe {to our children we take} for granted, we don't sort them out so that zinga affecti ingqondo zabo {they don't affect their mind}.
P5	45:58	And another thing thina {us} as parents esiyenzayo singarealise-I is that thing yoba yhooo umntana ka bani uclever ukha 10/10 umntana ka bani then owakho xa efumene 6/10 uthi udom. { that we as parents do without realising, is that thing where you have a so-and-so's child who is clever and gets 10/10 and then your child who gets 6/10 you say they are dumb} [P2: Comparing kids, ya] That's another bad behaviour for thina {us} as parents. We don't check uba umntana {with our child} what are they struggling with eskolweni {at school}, sithi hai umuncu lo, udom {we say that no they are dumb} like his father or his uncle. [Participant: Hmmm] [P1: Laughs] So now it will be even difficult for even that child to try because uyayazi {you know} even if he tries - okay maybe I do wrong "wow, ndizoba ngu dommy" {"I'm going to be a dummy"}. They gonna call me dommy. [Group laughter] Uyaybona {you follow me?} Because you find that as parents sinala attitude ubone uba sithanda uadmirisha abanye abantu {We have the attitude where you see that we admire other people's children}. You don't take into account uba nathi we still huma beings, nomntana naye {and the child is too}. Abantwana soze bakhule ngokufanayo {(different) children do not develop in the same way}, never. And you will find that your child's neighbour ugood kwiMaths nakwenye into {is good at math and something else}. Owakho umjonga xa kudlalwa nje uthi hai umuncu {You look at your child when they play and you decide they are "sour" (off)}. Awumazi ukuba uyakwazi ukucula, awumazi ukuba uyayidlala imusic instrument zange wamtrya nomtrya kwezazinto. Uthi udom,makahlale apha endlini {You don't know he could sing, you don't know if he can play a musical instrument as you've never tried. You say they are dumb and must stay in the house}. Yabo {you see} that's another thing also as parents. Sometimes unala anger uba utatomntana zange andihoye kwatsha kwacima kwathini {you take out the anger you have because the child's father didn't take care of you, and so on}. Now you have a new boyfriend, you have a second child, the old child is going to take a seat back. Anything that is coming, if you buy something new, uqala kuloomntana {it starts with *that* child} because utatakhe {his father} is active and is in the picture. So thina {we} as parents nathi we need reprogramming.
P2	48:00	Reprogramming on how to develop a child's brain. Because sometimes it's not the child's brain that is under-developed, it's the parents. [P5: Exactly! Exactly! Exactly, you want your child to play i-rugby, to play i-cricket, nooo maybe your child is a musician, uyabon?, That's my view.]
Jac	48:33	So, in terms of parents need to be helped to understand what their seeing **…** for a screening or a questionnaire like this - should there be a person but also extra explanations at the- [P4: Kawuphinde? {Please repeat}]
P2	49:02	The questionnaire was beautiful. It made me think of the other things that the kids pha endlini {at the home} do that I thought were normal but aren't really. Indinike {it has given} so much information la questionnaire. I loved it.
P1	49:35	Okay to add on to what *P2* is saying, ne, I think we as parents, especially black parents we are quick to judge abantwana bethu kwimistakes abazenzayo {our children for their mistakes}, like, not taking into consideration that some of the things, they are part of idevelopment yomntana wakho {part of the child's development}. [Participant: Hmmm]

		Because if you as a parent say to your child, "You are stupid", "you can't do this" or you even force your child kwinto angayithandiyo {into something they don't like}, you are also contributing kwi-low self-esteem yomntanakho {of your child}. And choosing i-career or sports that umntana funeke asenze {the child has to do} is not right. The only role that a parent should play ebomini bomntana {in the child's life} is to support the child and even ask ubana "do you think that le career uyifunayo or esisport sizokwenzela ntoni in return"? {that the career or sport you want to do will be (rewarding)}. [P2: Support, support] [P5: Yeeees] So thina {us}, we need to support abantwana bethu {our children}. And most of us sifuna ukuba ziikgrokgro ebantwaneni bethu {we want to be monsters to our kids}. Basoyike {they are afraid}
P5	51:26	Can you explain ku*Jac* ikgrokgro? [Group laughter] [P3: Like a vampire]
P1	51:40	Sifuna ubazimonster {We want to be monsters}. Fine kengoku umntana uyakoyika. Hlambi kubekhona ubhuti oye wasexual abuser umntanakhi. Do you think umntana ke ngok uzokwazi ukuxelela? Xa ekoyika uzoxelela omnye umntu okanye abonwe nguMiss. {Fine and then the child is scared of you. Maybe some man sexually abused your child. Do you think your child will be able to tell you? When they are scared of you, they will explain to someone else or the teacher} [P6: No**,** ikgrokgro] How will you feel as a parent umntanakho abonwe ngomnye umntu into anayo {when your child is telling someone else what they have}? Ube wena ungamboni? {And you don't see them?} [P5:Uyikgrokgro kaloku {You're a monster}] Ngenxa yeactions zakho kalok {because of your actions} because one of i-reasons for abazali ukubazikgrokgro ebantwaneni {parents to become monsters to their children} is to protect them **…** from izinto zalapha emhlabeni {things in the world}. But ke as a parent funeke ube yitshomi yomntanakho {you must be a friend to your child}, with i-disability or not.
MLD	53:03	If I understand correctly that you are saying that um **…** that we expect rewards from our children?
P2	53:26	Ha.a {no}, we expect that the kids must change their lives to adapt to whatever we want them to do. If mna {myself} as a parent I expect my child to be an A student because eskolweni {at school} because I was an A student and I never missed school, was never sick, played 1st team netball and water-polo, my child needs to live up to those things, whereas my child is not someone like that. My child likes to draw, and my child likes to be with her friends and socialise [MLD: Okay ndiyabona {I follow}]
Jac	54:27	Let me go back to child development and neuro development, like there's a lot of questions we saw that are concerning, but I want to check how much understanding you think parents have of specific conditions for example your autism, dyslexia, ADHD, tell us how much awareness you think there is. Would parents go to that conclusion? [MLD: If they see certain symptoms or behaviour do they think, "Oh maybe it's ADHD or maybe it's dyslexia."]
P2	55:21	Okay, can I talk? So, most of the time abazali {parents} **…** don't take into consideration that kukho i-illnesses ezinjalo {there is such an illness}. Once umntu abone umntana unebehaviour "e-abnormal" ucinga uba yhu lomntana unedisability or uzondisokolisa, funeke asiwe kwizinto ezispecial like schools. {Once a person sees the child has "abnormal" behaviours, they think that, wow, this child is disabled or is going to bother me and must be taken to a special facility}. You don't think about i-well-being yomntana - izothini because ubona iisymptoms ingathi uyagula {of the child - what they will say because you see their symptoms as being illness}. Most of the time black parents also banento ethi hai umntanam uthakathwa ngumeza or ungayi kwameza because bakutyisa inton nton then yakwenza waba-hyper kakhulu {they will say something about the child being bewitched by a knife or in the throat because they eating nothing

		or they are then made very hyper}. At the time umntana uneADHD {the child has ADHD}, you didn't sit and consider things like that. So, there's a lot of lack of knowledge of these illnesses in black communities. So, we tend to not think that umntwana uneproblems {the child has problems}. Once umntana abonakale engathi unezezifo we say yhu umntana wakho sisdalwa, funeke aye eDorothea {Once the child in looking diseased we say, oh, your child you've made needs to go the eDorothea [special needs school]}
P1	57:19	Ya, *P2* ne, ukongeza kulento uyithethayo, once umntanakho afunde kwispecial school, like apha {in addition to what you are saying, once your child studies at a special school, like here in -} eStellenbosch we only know of one, Dorothea, once umntana afunde pha uba yintlekisa kwabanye abantwana {it becomes a joke to the other children}. Not knowing that ukhona i-disability {there is disability} - there is a reason why ekhutshwe kwiskolo ebefunda kuso {they got expelled from the school they attended}. Abantwana bethu, nathi thina bazali, don't know if sicinga iDorothea akkufundwa or enoba mhlambi bafundiswa ooABCD. And abantwana bethu ukuze bajudge abantwana abafunda eDorothea isuka kuthi - thina bazali - Uthi woxelelwa ngugqirha kukuba umntana unedisability ucinge uba yhooo ndizopayer uSassa, because siyazithanda iibenefits ufuna upayer, but what about the things umntana azozineeda? {Our children, and we as parents, don't know if we think that at Dorothea they can read or if that group is taught ABCs. And children judge the kid's who study at Dorothea - we parents - they are told by the doctor the child has a disability, wow, I'm going to get paid by SASSA, because we love the benefits, you want to be paid, but what about the things the child needs?}
MLD	58:54	What I think you're saying Sisi is that parents could think, when the doctors or somebody says there is a disability, they think that "Oh, I am going to be financially supported", not "Wow, what are the next steps to help this child"? [Participants murmur agreement] [P2: Yes] Or help him with his potential. Because the disability may be there, but, um, it does not his abilities cannot be wonderfully developed. [P2: Can't be developed]
P3	59:39	I think we just too ignorant. We know something is wrong but then we keep quiet, or we just sit back knowing there's something wrong happening with the child.
P1	59:53	Ya, we are too procrastinating, because when you know the truth and you don't want to accept it, you can do something very stupid, because you can see man when something is wrong. Whether you are stupid or not, but you can see. But people tend to think that people who are living with disabilities are stupid **…**
	1:00:21	(…….)
P1	1:00:48	I think uThixo ikhona into ayibekileyo kumntu onedisability a-excella kuyo, better than wena mntu o"normal" {I think God has something is store for a person with a disability who is better than you, as a "normal" person.} [P3: Ehh! {Yeah!}]
P2	1:00:58	And then thina {us}, as abazali {as parents}, we stigmatize them because umntana [portion of audio missing] umntwana autistic {an autistic child} or who has ADHD or which is dyslexic akakho {he is not} disabled but u-"specially abled". We find disabilities in things that aren't. Umntana onjeya unezinto azenza ngendlela yakhe qha {Such a child has his own way of doing things}.
P1:	1:01:32	For instance, abanye abantwana ziislow learners but thina, ukhubone xa kusithiwa usisqonda mva or kuthiwe, "wow, uzothetha imini yonke" or funeke ucaciselwe iveki yonke {other children are slow learners, but us, we see when we understand, it later gets said that "wow, they talk all day" or it is necessary to explain the whole week}. It's not that ba sick, qha it's just that they need more attention.

Jac	1:01:52	And, um, we're reaching the end soon of the focus group, I love how everyone had so much to say and how passionately they said it, uhm, let me just check that my audio is on (chuckles) **…** I just wanna check with the men, as well, any closing remarks? [P2: Hey Jacques, we going to women's month tomorrow so women must dominate] [Group laughter] [P2: Come on guys say something] [MLD: Majita {Gents}]
P6	1:03:09	Okay, back to the topic, mna {myself} I believe in one thing, when you notice uba umntana une actions ezifunny, yiya eskolweni {When you notice the child has funny actions, go to the school}. I suggest umzali aqale pha then aye ekliniki or udibane neesocial worker {I suggest parents start there and then they go to the clinic or meet a social worker}. Ekliniki I think kulaphole questionnaire ingasebenza {At the clinic I think this is where the questionnaire can work}. **…** [Audio quality dropped and a portion of the discussion is missing] If i-translated, ingakuxelela if umntana unengxaki phi {It can tell you whether the child has a problem}. If not translated, definitely akhonto ingaphinde ilunge {nothing can be correct} because le questionnaire inceda {helps} eza problems ze language barrier. Kuzohlala kune {There will always stay (a)} barrier between the health care worker and the parent and nawe as umzali akuzubalula ukuchaza into erongo with umntana because of le ngxaki {we as parents will not find it easy explaining something that is wrong with the child because of this issue}.
Jac	1:05:15	Thank you so much everyone with the fantastic focus group work. Basically, what happens with the focus group work is we, on our side, write it out and we do a systematic analysis. So again its anonymous. We don't discuss anyone personally, we look if the themes popped up across what we discussed.
	1:06:01	(……)

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APPENDIX F

SUMMARY TABLE OF THEMATIC ANALYSIS RESULTS

Category 1: Clinical Dynamics Impacting Support and Detection

Major Theme: **LANGUAGE BARRIERS**	
Minor Theme 1: "It's a problem of language"	
Sub-theme 1: "You don't understand what does it mean"	"Most medicine is not written in isiXhosa […]" "[The] doctor – she's a Indian or a young White or a young Coloured lady. Obviously, she won't be able to speak your language …" "It's a problem of language […]" "And then if the person {he can't talk} English […] they can't hear what [the doctor] says is wrong with them." "And sometimes […] at {the clinic} they do give you {the pamphlet}, "read this, read this" – yeah, you can read something but as a parent you don't understand what does it mean?" "If [documents are] not translated, definitely nothing [discussed] {can be correct}."
Sub-theme 2: "You don't know what the word is"	"{The language is then a struggle because you don't know what the word is for an "Epileptic Seizure" in English.}" "{But when [the school] called external people, they said nothing was wrong with the child … but maybe it was because of a language barrier and a lack of information.}" "{There will always stay a} barrier between the health care worker and the parent and {we as parents will not find it easy explaining something that is wrong with the child because of this issue.}"
Sub-theme 3: "You feel stupid as a person"	"{When you ask the doctor what they said, they tend to make a spectacle of you.}" "Exactly, stigmatized!" "{You find them asking why you do not know English at this age […] so now they will take you from the consultation room into the corridor just so they can embarrass you in front of everyone and make you feel stupid}." [Quoting the doctor:] "How come we don't understand this?" "{You don't know English, maybe you don't know Afrikaans – you feel stupid as a person"} "I don't see any reason why people must be ashamed of {their home language}. If you don't understand {something in their language}, you have a right to ask."

Minor Theme: "It can tell you whether the child has a problem"	"The [A-TAC] questions are very good, for everyone […] I think its gonna work for everyone, even the ones that didn't go to school, they can understand the questions." "We are coming [from] areas where we speak our native language isiXhosa […]" "{When you go to a healthcare facility […] the nurses that work at the particular clinic, when there is a parent who has problems with language, maybe there should be someone to help them translate.}" "I think we need more people, like, at the clinics […] {let there be a designated individual who is the translator.} "If i-translated, [a document] {it can tell you whether the child has a problem.}"
Major Theme: **HEALTHCARE DISILLUSIONMENT**	
Minor Theme: "No one is explaining anything"	"So sometimes there is no space for our parents to – for someone to explain to them." "[The doctor] will give them medication, and they will pay and no one is going to say 'Mama, you see this, this medicines is for this and this, and this is the side effects' – no they don't do that […] no one is explaining anything to them." "{If a person gets medicine or an injection, they leave without a good understanding of} what the doctor said."
Minor Theme: "It is not private anymore, everybody knows"	"Sometimes as parents, it is not easy to speak out, or – {you are trying to explain and there are other people}." "The person [healthcare staff] who is gonna ask will say 'Eh, sis, do you understand this [pamphlet]?' and sometimes she is asking you and there are other people around you – and you're gonna say '{Yes}, I understand', not – {I don't want to look dumb}." "[…] so now they will take you from the consultation room into the corridor just so they can embarrass you in front of everyone and make you feel stupid}." "It is full {at the clinic}, inside and outside – people are watching you, like there is something wrong with you […] {some of us are sensitive}." "[There are] people who know when your name is being called on Room 9, you are going to take chronic for HIV, so when you are being called on room 5, you are going to take i-treatment for TB […] because it is not private anymore, everybody knows."
Minor Theme: "It is always full, all the time"	"{At} public clinics, it is not the same like the private sector, or Medi-clinic – {it is always full}, all the time." [Description of healthcare staff:] "[…] {someone who is going to leave, who is maybe at a desk inside and tells you} 'I have a patient inside'."

	"There is going to be no space because the majority of people are going inside." "Because, another thing, going back to the clinic, is not easy, {you will not be first, and there will be at least 10 people}." "{No, you come and there are} other people and it is full {at the clinic}." "{You are right […] the doctor will have an excuse they give a person […] they will not explain to people, and will just say that they are tired and that, no, they have other patients and so cannot help}." [Quoting the doctor:] "'I have a lot of queue outside', yeah."
Minor Theme: "This is my responsibility to get across to people"	"If someone doesn't understand the question, they can ask the person sitting next to them 'what is this question, can you explain this question to me?'" "I think we need more people, like, at the clinics, more people like social workers […] {a person that knows that 'this is my responsibility to get across to people} […] I am translating for people, people need to understand this'}." "Even if not inside the clinics, maybe a container outside – maybe there is going to be two or three people who are sitting there." "It is our job to observe our kids and look what the child's problems are." "I am the one {that can see that} maybe my child has a problem." "Most of the time {the child is truly seen} first by the parent and then the parent decides [how to manage]." "We never find people who ask us the [A-TAC] questions that are asked […] If we had people that asked these questions when you have a child initially [the parent would consider potential problems]". "I think I would first go to the teacher, find out how is the child in the class." "{Myself}, I believe in one thing, {when you notice the child has funny actions, go to the school}.

Category 2: Parental Understanding of Child Development

Major Theme: **CONCEPTIONS OF CHILD DISABILITIES**
As the group had just worked through the A-TAC screen, conceptions of child difficulties that appeared to be 'once-off' references were discounted. However, themes that repeated themselves emerged, and are discussed below. A key branching quote, to link concerns of the previous category to the current one are: "Comparing kids, yah." "We have the attitude where you see that we admire other people's children. You don't take into account […] we're still human beings, {and the children. Children do not develop in the same way}, never."

Minor Theme: "We tend not to think that the child has problems"	"So other medicines that are – that can be used to cure other illnesses that is happening with children around the home, we don't know anything about that." "{We are} ill-informed about things like i-autism." [Regarding punishment:] "[…] not knowing {that they are troubled}." "Not taking into consideration that some things, they are part of {the} development {of the child}." "[Parents] don't take into consideration that {there is such an illness}." "At the time {that the child has AD/HD}, you didn't sit and consider things like that." "So, there is a lack of knowledge of these illnesses in black communities." "So, we tend to not think {that the child has problems}." "I think we are just too ignorant."
Minor Theme: "After the trauma they cannot return to being themselves"	"If the parents put stigma on what is going on with the child, the child then {when they go out} … {it starts in the home}. "We notice {he sometimes urinates while sleeping […] when he sleeps, he seems to be in the playground, then his mother also says he could be dreaming about what was happening to him because he is bullied}." "{The child cannot report what happens to parents because they are scared}." "Maybe try and recall a time when the child got some traumatic experience that maybe made the child develop things […] {because some things are caused by trauma in their mind, then after the trauma they cannot return to being themselves}." "{You take out the anger you have because the child's father didn't take care of you, and so on.} Now you have a new boyfriend, you have a second child, the old child is going to take a back seat."
Minor Theme: "People tend to think that people living with disabilities are stupid"	"Some of the kids {they have} – they are having a lack of learning, they are having a lack of speaking, they are having i-lack of behaviour and moving and all of that." "{They said nothing was wrong with the child and he should be in mainstream school}." "{Once a person sees the child has 'abnormal behaviours', they think that, wow, the child is disabled and is going to bother me and must be taken to a 'special school'}." "{Once the child is looking diseased we say 'Oh, your child you've made needs to go to Dorothea [special needs school]}."

	"[…] there is a reason why {they got expelled from the school they attended}." "{Other children are slow learners […]}" "{We as parents don't know if we think that at Dorothea [the children] can read or if that bunch is taught ABCs}." "But people tend to think that people living with disabilities are stupid."
Minor Theme: "The child is being bewitched"	"Most of the time black parents also {will say something about the child being bewitched […] in the throat because they are eating nothing, or they are then made very hyper}."
Major Theme: **MANAGEMENT ROUTES OPTED FOR**	
Minor Theme 1: "You know the truth and you don't want to accept it"	[Description of some parents:] "[…] {when the child does something at school, you act like you don't know when you actually follow what happened}." "{You don't want to think} that your child is special." "[Something] we do as parents without realizing is that thing where you have so-and-so's child who is clever and gets 10/10, and then your child who get 6/10 […] {we say that no they are dumb} like his father or uncle." "We know something is wrong but we keep quiet, or we just sit back knowing there's something wrong happening with the child." "You know the truth and you don't want to accept it."
Minor Theme 2: "You need to help and monitor him"	
The thread of this category was most well-encapsulated by the following quotes: "I think I would firstly go to the teacher, find out how is the child in the class […] and then from there *mos*, most of the schools, maybe they have psychologists and all that, then I will ask them to help the child […] then if maybe they can't, then that is when you go to the social worker to try and find help." "{When you notice the child has funny actions, go to the school}. I suggest {parents start there and then they go to the clinic or meet a social worker}."	
Sub-theme 1: "We want to be monsters to our kids"	"{We as parents like to give the child a smack when they wet the bed, even before they are age 5}." "{We want to be monsters to our kids – they are afraid […] you're a monster because of your actions} because one of {the reasons} […] is to protect them from {things in the world}." "We expect that kids must change their lives to adapt to whatever we want them to do."
Sub-theme 2: "As parents we need reprogramming"	"I think it is the responsibility of the parent that they need to research the child's disability." "So, I think for us a parents, it is our job {to observe our child and to look what the child's problems are, and what do I as a parent do if my child has struggles?"

	[In the context of child training:] "Because in our community, we don't have social workers or {the} centres where they will teach […] so we need people from {Stellenbosch University to train people to do these things}." "Be aware and understand, and if the parent understands the child's situation, then they know how to help." "So {we} as parents we need reprogramming." [Participant response:] "Reprogramming on how to develop the child's brain. Because sometimes it is not the child's brain that is under-developed – it's the parent's."
Sub-theme 3: "We just need to help the child navigate through life"	[Visiting the doctor:] "You need to know what is happening, if he is having fits or seizures – and how you need to help and monitor him." "The healthcare workers and, uh, the parents have to find {an} understanding […] we just need to help the child navigate through life with whatever they have as a challenge." "I think it is your responsibility to tell the doctor about 'I have noticed this and this and that about my child." "{Maybe the doctor gives you feedback that the child has speech problems and refers you to consult with a speech therapist, then it is your responsibility now as the parent to understand how speech therapy is going to help}." "I suggest {parents start {at the school} and then they go to the clinic or meet a social worker}." [If the school cannot assist:] "Then that is when you go to the social worker to try and find help."
Sub-theme 4: "I suggest parents start at the school"	"I'm the one who needs to go to the school to address the problem of my child […] {my child is here to learn so the teacher} has to understand what is happening to my child." "{And when you go to the school, I think indicate that your child has a disability on the school forms, so that the school can maybe help and watch the child}." "Most of the schools, maybe they have psychologists and all that, then I will ask them to help the child." "I suggest {parents start at the school}."

APPENDIX G

MEMBER CHECK: RESULTS SUMMARY FOR PARTICIPANTS

The following study interviewed parents to see how they felt:

- About developmental problems in children, and how they would deal with such problems.
- About what they feel impacts the detection of child problems in public clinics.
- About how open they were to questionnaires that check on the child's development.

LANGUAGE IS A BARRIER		
Parents showed that language is a big problem at the clinics. This blocks them from being able to get proper help from the doctors – and so it becomes more difficult to help the child. There were different ways in which language is a problem:		
1. "IT'S A PROBLEM OF LANGUAGES"	**"You don't understand what does it mean"** **The parent may not understand the information given by doctors. Forms, instructions & medication are not translated into isiXhosa. So, parents then don't know what to do, what condition is present, or how to research the difficulty. This brings up a lack of clarity that blocks proper help for the child. The fact that very few doctors speak isiXhosa has been confirmed by other researchers.**	"Most medicine is not written in isiXhosa …" "[The] doctor – she's a Indian or a young White or a young Coloured lady. Obviously, she won't be able to speak your language …" "It's a problem of languages …" "And then if the person akakwazi ukuthetha English … akamva uba [ugqirha] uthe unantoni." "And sometimes … at ikilini, they do give you iPamphlet, [and say] "read this, read this" – yeah, you can read something but as a parent you don't understand what does it mean? Uyabona?" "If [documents are] not translated, akhonto ingaphinde ilunge."
	You don't know what the word is // "awuyazi uzothi yintoni" **If a parent does not know English, they will not be able to tell the doctor all the information they have about the child. The child's problems may then be dismissed or not properly noticed because of this barrier.**	"But ke ngoku nalapho ilanguage iyabetha because awuyazi uzothi ukuxhuzula yintoni ngeEnglish" "But xa sibiza abantu ba external, babe besithi lomntana okananix … ye barrier, kwilanguage, ndiye nakwi part ye lack of information." "Kuzohlala kune barrier between the health care worker and the parent and nawe as umzali akuzubalula ukuchaza into erongo with umntana because of le ngxaki."
	You feel stupid as a person // "ufeele ustupid as umntu" **This appears to be a new theme, and more research should be done on it. Doctors and health staff are seen as rude. They do not appear to sympathize with the parent's language difficulties. They may even shame the parent**	"Aabantu, sometimes, baye bafumanise xa ubuza ukuba ebesithi la gqirha, afuna ukushow-offa ngawe." "Exactly, stigmatized!" "Umntu akubuze kutheni ungayazi iEnglish umdala kangaka … so ke ngoku umntu asuke nawe kwiConsultation room aye ma naye kwiCorridor - afune embarrasa in front of everyone of which nawe ikwenza ufeele stupid." [Quoting doctors:] "How come we don't understand this?"

	for not understanding, and make the parent feel stupid. This may make a parent angry, because they have the right to asks things. Then the parent may not want to attend the clinic.	"Awuyazi iEnglish, mhlawumbi awuyazi iAfrikaans, ufeele ustupid as umntu." "I don't see any reason why people must be ashamed of ihomelanguage zabo. If you don't understand into ngelanguage yakhe, you have a right to ask."
2. IT CAN TELL YOU WHETHER THE CHILD HAS A PROBLEM // "INGAKUXELELA IF UMNTWANA UNENGXAKI PHI" **Parents brought up the need for better translation support. This is both for talking & documents. Properly translated forms help parents understand, help raise awareness for child difficulties, and help parents say what is wrong with the child. Such forms should be in simple language so everyone can understand. There is also need for clinic translators, which may require volunteers.**		"The [A-TAC] questions are very good, for everyone … think its gonna work for everyone, even the ones that didn't go to school, they can understand the questions." "We are coming to areas where we speak our native language isiXhosa …" "Xa uye kwihealth facility ne … oonurse abasebenza kuloo kliniki uye kuyo, xa kukho umzali onenxaki mhlawumbi yelangauge, fanele ukhona umntu oncedayo ukutranslate." "I think we need more people, like, at the clinics … makubekho lamntu oyi-one obekiweyo phana ifriend uba uyazi uba this is the person who is going to translate the language to people." "If i-translated, ingakuxelela if umntana unengxaki phi."
THERE IS UNHAPPINESS WITH THE HEALTHCARE SYSTEM		
Parents spoke about more reasons it is difficult to get help at the public clinics. These things create barriers to support. This is important to discuss, because if parents are upset or dissatisfied with the clinics, they may not want to go to them for help. This may make it harder to spot child difficulties, or to raise awareness.		
1. "NO ONE IS EXPLAINING ANYTHING" **Once again there is a lack of clarity at the clinics, as parents feel that doctors do not put any effort into giving full information or explanations. Parents thus do not have a good understanding of what happened in the session or what they need to do. This issue is seen in other studies too.**		"So sometimes there is no space for our parents to – for someone to explain to them." "[The doctor] will give them medication, and they will pay and no one is going to say 'Mama, you see this, this medicines is for this and this, and this is the side effects' – no they don't do that … no one is explaining anything to them." "If umntu ufumene imedicine or i-injection, wahamba engakhange a-understande kakuhle what the doctor said."
2. "IT IS NOT PRIVATE ANYMORE, EVERYBODY KNOWS" **There is a lack of privacy at the clinics. It is full and there is the feeling that everyone is watching you to figure out what is wrong with you. People know what different rooms are for, and parents may be scared of theirs or the child's diagnosis being known. Parents may also be scared of being blamed as parents or having their child judged. For this reason, people don't feel safe going to the clinic.**		"Sometimes as parents, it is not easy to speak out, or – uzama uku-explaina kukho abanye abantu." "The person [healthcare staff] who is gonna ask will say 'Eh, sis, do you understand this [pamphlet]?' and sometimes she is asking you and there are other people around you – and you're gonna say 'Ewe, I understand' … andifuni ukulook like "dom"." "It is full ekliniki, inside and outside – people are watching you, like there is something wrong with you … Abanye bethu ba-sensitive." "There are people who know when your name is being called on Room 9, you are going to take chronic for HIV, so when you are being called on room 5, you are going to take i-treatment for TB … because it is not private anymore, everybody knows."

3. IT IS ALWAYS FULL, ALL THE TIME // "SOLOKO KUCWELE, ALL THE TIME" **The public clinics lack the staff or space to properly help patients. This leads to cramped spaces and long waiting times. This shows an economic under-resourcing, as is commented you would not see these issues at a medi-clinic. The staff are also seen as busy, having many people to see in a day and so making 'excuses' to not have to properly explain information to parents. External people are need to help improve the health services, such as social worker or volunteers.**	"Kwi-public clinics, zethu, it is not the same like the private sector, or Medi-clinic – soloko kucwele, all the time." [Description of healthcare staff:] "Umntu ozosuka, mhlawumbi edesikeni yakhe athi uba 'I have a patient inside'." "There is going to be no space because the majority of people are going inside." "Because, another thing, going back to the clinic, is not easy, awuzo fika kukho abantu aba-yi-ten." "Hayi, uzofika, kukho other people and it is full ekliniki." "Unyanisile … ugqirha uzobane-excuse ubane-explaina to loo mntu because thina singabantu mos sinestyles - sindiniwe uyakwazi ukuthi hayi, ndinepatient andizomncedi lowa." [Quoting the doctors:] "'I have a lot of queue outside', yeah."
4. THIS IS MY RESPONSIBILITY TO GET ACROSS TO PEOPLE // "LUXANDUVA LWAM LO'KUBA MANDITRANSLATE THIS EBANTWINI" **There is a need for shifting the responsibility of 'child detection' from doctors to other individuals. Specifically, parents seemed to want to be empowered to do the initial monitoring for themselves. To do this, parents would need to have the right support, including 1) translators to help explain and 2) people asking about the right questions regarding the child. The parent is then the one to 'observe' and 'decide' how to manage the situation. If the parent has concerns, they may go to the school first. This suggests that perhaps the A-TAC should rather be used at schools.**	"If someone doesn't understand the question, they can ask the person sitting next to them 'what is this question, can you explain this question to me?'" "I think we need more people, like, at the clinics, more people like social workers … Umntu ozoyazi ukuba "luxanduva lwam lo'kuba manditranslate this ebantwini" … I am translating for people, people need to understand this'." "Even if not inside the clinics, maybe a container outside – maybe there is going to be two or three people who are sitting there." "It is our job uba si observe, abantwana bethu, and then sijonge ukuba ingxaki yom umntwana wam iphi ne." "I am the one ndiyabona uba maybe my child has a problem." "Most of the time umntwana ubonwa nyan nyan first by the parent and then the parent decides [how to manage]." "We never find people who ask us the [A-TAC] questions that are asked … If we had people that asked these questions when you have a child initially [the parent would consider potential problems]". "I think I would first go to the teacher, find out how is the child in the class." "Mna, I believe in one thing, when you notice uba umntana une actions ezifunny, yiya eskolweni."
HOW CHILD DEVELOPMENTAL ISSUES ARE SEEN	
There were different ways that parents explained the child might be thought of. It is important to understand these different versions, because they impact how a parent would choose to manage the situation of their child. 3 versions that popped up were that 1) parents may not spot the issues, 2) parents may think the child's behaviour comes from trauma, or 3) parents may think that these are the 'slow' children.	
1. WE TEND TO NOT THINK THAT THE CHILD HAS PROBLEMS // "WE TEND TO NOT THINK UMNTWANA UNEPROBLEMS"	"So other medicines that are – that can be used to cure other illnesses that is happening with children around the home, we don't know anything about that."

There appears to be a lack of information or knowledge of child developmental issues in the community. Parents may not realize that issues they see in their child are developmental, and so may just see the child as being 'naughty'. Thus, parents may not look for help with the child's difficulties.	"Si-ill-informed about things like i-autism." [Punishment is done:] "… not knowing ba yingxakileyo." "Not taking into consideration that some things, they are part of iDevelopment yomntwana wakho." "Abazali … don't take into consideration that kukho i-illnesses ezinjalo." "At the time umtwana uneADHD, you didn't sit and consider things like that." "So, there is a lot of lack of knowledge of these illnesses in black communities." "So, we tend to not think umntwana uneproblems." "I think we are just too ignorant."
2. AFTER THE TRAUMA THEY CANNOT RETURN TO BEING THEMSELVES // "AFTER LA TRAUMA UMNTU AGAPHINDE ABUYELE EKUBENI NGUYE" **A child being emotional, anxious or traumatised was another reason given for why they may show behaviour difficulties. The child have continuous stress (such as bullying or being poorly treated in the home) or suffering a bad traumatic event may create issues in the child.**	"If the parents put stigma on what is going on with the child, the child then xa emphumayo … kuqala iqala apha endlini." "We notice ukuthi sometimes uyachama xa elele … xa elele ingathi uyaphupha ngathi ukwiplay ground. Aphinde athi umamakhe lomntana udreama what was happening kuye kule bullying bayenzayo." "Umntwana akakwazi ukuyireporta lonto ebazalini because uyoyika." "Maybe try and recall a time when the child got some traumatic experience that maybe made the child develop things … because ezinye izinto zenziwa yitrauma ezinqgondweni zabo and then after la trauma umntu angaphinde abuyele ekubeni nguye." "Unala anger uba utatomntana zange andihoye kwatsha kwacima kwathini. Now you have a new boyfriend, you have a second child, the old child is going to take a back seat."
3. "PEOPLE TEND TO THINK THAT PEOPLE WITH DISABILITIES ARE STUPID" **Children with disabilities may be stereotyped as the unintelligent child who is a slow learner. This may also include the children whose issues are so severe, they 'look' disabled or diseased as well. These are kids you expect get expelled from normal school, and who will then have to go to a special needs school. Parents may feel shame or blame for having such a child. Parents also** **Mentioned that people love to compare kids in the community, and so parents may be afraid that if their child has developmental difficulties, people will think the child is just 'stupid'.**	"Some other kids, bane – they are having a lack of learning, they are having a lack of speaking, they are having i-lack of behaviour and moving and all of that." "Besithi lomntana okananix, lomntana fanele abe kwi mainstream schooling." "Once umntu abone umntana unebehaviour "e-abnormal" ucinga uba yhu lomntana unedisability or uzondisokolisa, funeke asiwe kwizinto ezispecial like schools." "Once umntana abonakale engathi unezezifo we say yhu umntana wakho sisdalwa, funeke aye e-[special needs school]}." "… there is a reason why ekhutshwe kwiskolo ebefunda kuso." "Abanye abantwana ziislow learners …" "Abantwana bethu, nathi thina bazali, don't know if sicinga [special needs school] akkufundwa or enoba mhlambi bafundiswa ooABCD." "But people tend to think that people living with disabilities are stupid."

<table>
<tr><th colspan="3">HOW TO MANAGE THE CHILD</th></tr>
<tr><td colspan="3">Once problems with the child have been properly spotted, the next theme deals with how parents may want to manage the child. This will depend on how the parent understands the child's difficulties. It must be noted that when parents choose to do something active about the child's problems, they appear to once again prefer going to the school for help. Health clinics are not necessarily the first option that is taken. This means intervention at places like schools must also be investigated more.
"I think I would firstly go to the teacher, find out how is the child in the class … and then from there mos, most of the schools, maybe they have psychologists and all that, then I will ask them to help the child … then if maybe they can't, then that is when you go to the social worker to try and find help."
"I suggest umzali aqale pha [at the school] then aye ekliniki or udibane neesocial worker."</td></tr>
<tr><td>1. "YOU KNOW THE TRUTH AND YOU DON'T WANT TO ACCEPT IT"

Parents may choose not to do any thing about the child's difficulties. This could be because 1) they are not aware of developmental issues, 2) or they go into denial because they do not want to think that their child is 'special'. They also do not want to deal with the stigma of having a 'special' child. Parents then find excuses for the child's behaviour or procrastinate in doing anything.</td><td colspan="2">[Description of some parents:] "… uba ungumzali kuthiwa umntana wenze into ethile esikolweni, upretende ngathi awuyazi kodwa uyayazi."
"Awufuni ukucinga that your child is special."
"Another thing thina as parents esiyenzayo singarealise-I is that thing yoba yhooo umntana ka bani uclever ukha 10/10 umntana ka bani then owakho xa efumene 6/10 uthi udom … sithi hai umuncu lo, udom like his father or his uncle."
"We know something is wrong but we keep quiet, or we just sit back knowing there's something wrong happening with the child."
"You know the truth and you don't want to accept it."</td></tr>
<tr><td rowspan="2">2. HOW TO HELP AND MONITOR HIM // "ANGACEDWA YINTONI OR UMTHINI UMONITORIDHE KANJANI"</td><td><u>We want to be monsters to our kids // "Sifuna ubazimonster ziikgrokgro ebantwaneni bethu"</u>

Parents may want to shape the children's behaviours by using discipline or punishment, such as a 'smack'. This is because a child must obey the expectations of the parent, and the parent tries to use 'tough love' in order to get the child ready for life. It is argued this option is especially true if the child's behaviours are seen as intentionally 'naughty'.</td><td>"Thina singabazali siyathanda ubetha abantwana xa bechamile bengena 5."
"Sifuna ukuba ziikgrokgro ebantwaneni bethu. Basoyike … Ngenxa yeactions zakho kalok because one of i-reasons for abazali ukubazikgrokgro ebantwaneni because one of i-reasons for abazali ukubazikgrokgro ebantwaneni is to protect them … from izinto zalapha emhlabeni."
"We expect that kids must change their lives to adapt to whatever we want them to do."</td></tr>
<tr><td><u>"As parents we need reprogramming"</u>

Parents spoke about how there is need more training and more awareness of developmental issues. This would be so that parents can 'reprogram' them-selves to better observe the child and better manage potential issues. This is also phrased as a</td><td>"I think the responsibility as a parent yakho funeke wenze is to research about idisability yomtnwana wakho."
"So, I think for us as parents, it is our job uba si observe,abantwana bethu, and then sijonge ukuba ingxaki yom umntwana wam iphi ne, and what do I as a parent do if umntwana wam unenxaki ethile?"
[In the context of child training:] "Because in our community, we don't have social workers or iCentres where they will teach … so we need people from</td></tr>
</table>

	responsibility of the parent. The more the parent knows about children, then more they know about what next steps to take. It was also said that it is the job of the parent to 'research' the disabilities. However, given the current lack of resources, it is necessary for volunteers and community workers to come in and offer such training.	eYunivesathi Stellenbosch otraine abantu bazokwenza ezi zinto." "Ube aware and iunderstanda and if umzali uyaiundaerstanda isituation yomtwana wakho, uyayazi indlela ukumnceda" "So thina, as parents, we need reprogramming." [Participant response:] "Reprogramming on how to develop the child's brain. Because sometimes it is not the child's brain that is under-developed – it's the parent's."
	I suggest parents start there [the school] // "I suggest umzali aqale pha [at the school]" **Parents showed hope that the school would be a good first place to look for support. The hope is that the school will have additional resources and care staff, in order to offer support to the child, and that the teacher can also watch and support the child. This indicates that it is important to parents that the child's learning be managed. It also suggests that teachers also have a responsibility to know about developmental issues and support the child.**	"I'm the one who needs to go to the school to address the problem of my child … umnt'nam uye pha for ufunda so umiss womntwana has to understand what is happening to my child." "Xa uzoaplyela isikolo, ne, I think paya kwiapplication form ikhona indawo ethathayo uba umntwana unayo isickness or unayo idispibility, so that if esikolweni mhlabi uyanceda ujongwa, hlwmbi ununmntana ofuna." "Most of the schools, maybe they have psychologists and all that, then I will ask them to help the child." "I suggest umzali aqale pha [at the school]."
	"We just need to help the child navigate through life" **Parents are reluctant in their need to see a doctor about the child's difficulties. They would prefer to first consult the school or social workers. If parents must go to the clinics, there is the hope that the doctors and health staff will reach some 'middle ground', and behave professionally for the sake of the child. In an ideal situation, the parent is aware enough to already know what they are looking for help with, and can get the doctor to give clear advice on that specific issue. From that point onwards, the parents recognize it will likely become their job to take over**	[Visiting the doctor:] "Funeke ubuze engoku into yoba xa ethe mhlawumbi uyaxhuzula or unefits ubuze angancedwa yintoni or umthini umonitorishe kanjani." "The healthcare workers and, uh, the parents have to find i-understanding … we just need to help the child navigate through life with whatever they have as a challenge." "I think it is your responsibility to tell the doctor about uba 'I have noticed this and this and that about my child." "Then ke if ugqirha ubuyele kuwe, wathi no, umntwana akakwazi ukuthetha kakuhle, funeke udibanise nespeeck therapist … then wena ke ngoku umzali it is your responsibility to know uba ispeach therapist sisomnceda njani." "I suggest umzali aqale pha [at the school] then aye ekliniki or udibane neesocial worker." [If the school cannot assist:] "Then that is when you go to the social worker to try and find help."

	management again, as the doctor will not remain involved. In the regard, even if the child is referred to a new professional, it will probably still be the parents job to figure out why for them-selves.	

APPENDIX H

EXAMPLE EXCERPT OF ORIGINAL A-TAC

In the original A-TAC structure, 'scored questions' towards a predictive cut-off score are those that fall above the solid line. These are referred to as the gate questions. Nonetheless, the researcher prioritized adapting the top gate questions, to support future validation research. Questions below the solid line serve to flesh out supplementary clinical insight regarding a child.

A. Motor control	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life**	Yes	Yes, to some extent	No
1	Does he/she have problems coordinating movements smoothly?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question:			
A1	Is he/she clumsy?	☐	☐	☐
A2	Is he/she fumbling?	☐	☐	☐
A3	Does he/she have balance problems?	☐	☐	☐
A4	Does he/she easily stumble and fall?	☐	☐	☐
A5	Have the peculiarities or problems relating to motor control caused significant impairment in school, among peers or at home?	☐	☐	☐
A6	Do the peculiarities or problems relating to motor control cause him/her significant suffering?	☐	☐	☐
A7	At what age did the peculiarities or problems relating to motor control commence?	Age:		
A8	Are they still present?	Yes ☐ No ☐		

B. Perception	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life**	Yes	Yes, to some extent	No
2	Does he/she seem disturbed by height differences such as in connection with climbing stairs etc.?	☐	☐	☐
3	Does he/she have difficulty judging distance or size?	☐	☐	☐
4	Is he/she oversensitive to touch or tight clothing?	☐	☐	☐
5	Is he/she particularly sensitive to certain sounds/noise?	☐	☐	☐
6	Is he/she particularly sensitive to certain flavours, smells, or consistencies?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to any of these questions:			
B1	Does he/she have difficulty comprehending orientation and spatial directions, e.g. puts clothes on backwards?	☐	☐	☐
B2	Does he/she often bump into other people?	☐	☐	☐
B3	Does he/she have poor concepts of time?	☐	☐	☐
B4	Does he/she have difficulty imitating other people's movements?	☐	☐	☐
B5	Does he/she have difficulty recognizing people?	☐	☐	☐
B6	Have the peculiarities or problems relating to perception caused significant impairment in school, among peers or at home?	☐	☐	☐
B7	Do the peculiarities or problems relating to perception cause him/her significant suffering?	☐	☐	☐
B8	At what age did the peculiarities or problems relating to perception commence?	Age:		
B9	Are they still present?	Yes ☐ No ☐		

APPENDIX I

A-TAC TRANSLATION: AFRIKAANS WORKSHEET

All isiXhosa A-TAC Draft and Final Versions of Items

Key: A1 = Original Translation. AF = Final Version. (*A**) = (Root Version Used). E1 = Original English Version. E2 = Adjusted English Version. No focus group scores are available.

A. Motoriese beheer // Motor Control	
1.	E. Does he/she have problems coordinating movements smoothly? E2: Does he/she struggle to manage movements smoothly? A1: Ervaar hy/sy probleme om beweging egalig te koördineer? A2: Ondervind hy/sy probleme om bewegings egalig te doen? AF (A2): Ondervind hy/sy probleme om bewegings egalig (*evenly*) uit te voer (*to execute*)?
B. Persepsie // Perception	
2.	E: Does he/she seem disturbed by height differences such as in connection with climbing stairs etc.? E2: Does he/she seem to have an issue with height differences, such as with climbing stairs etc.? A1: Lyk hy/sy gesteur deur hoogteverskille soos met betrekking tot trappe klim ens.? AF: Lyk dit asof hy/sy 'n probleem het (*has a problem*) met hoogteverskille bv om trappe te klim ens.?
3.	E: Does he/she have difficulty judging distance or size? E2: Does he/she have difficulty telling how large or far away something is? A1: Sukkel hy/sy om afstand of grootte te skat? A2: Vind hy/sy dit moeilik om te bepaal hoe groot of hoe ver iets is? AF (A1): Sukkel hy/sy om afstand of grootte te skat (*estimate*)? [*the first one ended up being preferable, and also coincides with the first version being preferable in the isiXhosa version as well*]
4.	E: Is he/she oversensitive to touch or tight clothing? E: Is he/she oversensitive to being touched or to tight clothing? A1 & AF: Is hy/sy oorsensitief vir aanraking deur ander mense (*touch from others*) of stywe klere?
5.	E. Is he/she particularly sensitive to certain sounds/noise? A1: Is hy/sy veral sensitief vir sekere klanke/geraas? [*sentence carries direct meaning to the original*]
6.	E: Is he/she particularly sensitive to certain flavours, smells, or consistencies/textures? E2: Is he/she particularly sensitive to certain flavours, smells, or the feel/texture of things like a scratchy jersey? [An adaptation that was made necessary by the isiXhosa version of the screen] A1: Is hy/sy veral sensitief vir sekere geure, reuke of konsistensies? [*konsistensies is pulled from English*] AF: Is hy/sy veral sensitief vir sekere geure, reuke of tekstuur (*textures*) soos 'n trui wat krap?
C. Konsentrasie en Aandag // Concentration and Attention	
7.	E: Does he/she often fail to pay close attention to details or make careless mistakes in schoolwork, or other activities? A1: Versuim hy/sy gereeld om fyn op te let na besonderhede of maak hy/sy sorgelose foute in skoolwerk, of ander aktiwiteite?

	A2: Versuim hy/sy gereeld om fyn op te let na besonderhede of maak hy/sy onnodige foute in skoolwerk, of ander aktiwiteite? AF: Versuim hy/sy gereeld om fyn op te let na besonderhede of maak hy/sy agterlosige foute in skoolwerk, of ander aktiwiteite? [*sentence carries direct meaning to the original*]
8.	E: Does he/she often have difficulty keeping/sustaining attention in tasks or play activities? A1: Sukkel hy/sy dikwels met die handhawing van aandag in opdragte of spelaktiwiteite AF: Sukkel hy/sy dikwels om aandag te behou in opdragte of speelaktiwiteite? [*sentence carries direct meaning to the original*]
9.	E: Does he/she often seem not to listen when spoken to directly? A1: Lyk dit dikwels of hy/sy nie luister wanneer daar direk met hom/haar gepraat word nie [*sentence carries direct meaning to the original*]
10.	E: Does he/she have difficulty following instructions and finishing tasks? A1: Sukkel hy/sy met instruksies volg en om take te voltooi?
11.	E: Does he/she often have difficulty organizing tasks and activities? A1: Sukkel hy/sy met die organisering van take en aktiwiteite? [*sentence carries direct meaning to the original*]
12.	E: Does he/she often avoid tasks that require sustained mental effort/focus (such as homework)? A1: Vermy hy/sy dikwels take wat volgehoue psigiese inspanning verg (bv. huiswerk)? AF: Vermy hy/sy dikwels take wat volgehoue fokus (*sustained focus*) verg (bv. huiswerk)?
13.	E: Does he/she often lose things? A1: Verloor hy/sy dikwels goed [*could be mistaken for "loses well"*]? AF: Verloor hy/sy dikwels items (*items/things*)?
14.	E: Is he/she easily distracted or disturbed? A1: Word sy/haar aandag maklik afgelei of word hy/sy maklik gesteur [*sentence carries direct meaning to the original*]
15.	E1: Is he/she often forgetful in daily activities? E2: Is he/she often forgetful in daily activities, e.g., doing the dishes? [extension necessary from isiXhosa version] A1: Is hy/sy dikwels vergeetagtig tydens daaglikse aktiwiteite, bv. om skottelgoed te was? [*sentence carries direct meaning to the original*]
D. Impulsiwiteit en aktiwiteitsvlakke // Impulsivity and Activity-levels	
16.	E: Does he/she have difficulties keeping his/her hands and feet still or can he/she not stay seated? A1: Sukkel hy/sy om sy/haar hande en voete stil te hou of kan hy/sy nie aanhou bly sit nie?
17.	E: Does he/she get up and move about in class or in other situations when he/she is supposed to remain seated? A1: Staan hy/sy op en beweeg rond in die klas of tydens enige ander situasie wanneer hy/sy moet bly sit? [*sentence carries direct meaning to the original*]
18.	E: Does he/she often run around or climb excessively compared to peers? A1: Hardloop hy/sy baie rond of klim oormatig baie in vergelyking met sy/haar portuurgroep?
19.	E: Does he/she have difficulty playing calmly and quietly?

	A1: Sukkel hy/sy om rustig en stil te speel? [*sentence carries direct meaning to the original*]
20.	E: Does he/she often act as though he/she had "ants in his/her pants", i.e., unable to stay still? A1: Tree hy/sy gereeld op asof hy/sy "miere in sy/haar broek" het, d.w.s. is nie staat om stil te sit nie? AF: Tree hy/sy gereeld op asof hy/sy "rooi miere" het (*"has red ants" [idiomatic expression]*), d.w.s. is nie in staat om stil te sit nie?
21.	E: Does he/she talk constantly? A1: Praat hy/sy voortdurend? [*considered a "better/proper" Afrikaans sentence*] A2: Praat hy/sy aanmekaar? AF: Praat hy/sy aanhoudend? [*considered a more understandable Afrikaans sentence*]
22.	E: Does he/she often blurt out answers to questions before they are completed? A1: Skree hy/sy dikwels antwoorde op vrae uit voor die vrae klaar gevra is? A2: Onderbreek hy/sy die spreker dikwels met antwoorde op vrae voor die vrae klaar gevra is? AF (A1): Skree (*shout out*) hy/sy dikwels antwoorde op vrae uit voor die vrae klaar gevra is? [*considered the 'more understandable' sentence in contexts*]
23.	E: Does he/she have difficulty waiting their turn? A1: Sukkel hy/sy om vir sy/haar beurt te wag?
24.	E: Does he/she often interrupt, or intrude on, others? A1: Val hy/sy dikwels ander in die rede, of pla/hinder (*bother/intrude*) hy/sy dikwels ander?
25.	E: Does he/she easily get bored? A1: Raak hy/sy maklik verveeld? [*sentence carries direct meaning to the original*]
E. Leer // Learning	
26.	E: Has he/she had more difficulties than expected acquiring reading skills? A1: Het hy/sy meer gesukkel as verwag om leesvaardighede aan te leer? [*sentence carries direct meaning to the original*]
27.	E: Is learning slow and laborious/effortful for him/her? A1: Leer hy/sy stadig en moeisaam? [*sentence carries direct meaning to the original*]
28.	E: Does he/she have difficulties with basic maths? A1: Sukkel hy/sy met basiese wiskunde? [*sentence carries direct meaning to the original*]
F. Beplanning en organisering van take // Planning and Organizing Tasks	
29.	E: Does he/she have difficulty shifting a plan or strategy when it is required? A1: Sukkel hy/sy met 'n verandering van plan of strategie wanneer dit nodig is? [*sentence carries direct meaning to the original*]
30.	E: Does he/she have difficulty keeping things in order around him/her? A1: Sukkel hy/sy om dinge rondom hom/haar in orde te hou? AF: Sukkel hy/sy om dinge in sy/haar omgewing in orde te hou? [*sentence carries direct meaning to the original*]

G. Geheue // Memory	
31.	E: Does he/she have difficulties remembering where he/she put things? A1: Sukkel hy/sy om te onthou waar hy/sy goed gesit het? AF: Sukkel hy/sy om te onthou waar hy/sy items (*items*) gesit het?
32.	Does he/she have difficulties remembering long or multiple-step instructions? A1: Sukkel hy/sy om lang opdragte of instruksies met baie stappe te onthou?
33.	Does he/she have difficulties learning rhymes, songs, multiplication tables etc by heart? A1: Sukkel hy/sy om rympies, liedjies, maaltafels ens. uit sy/haar kop te leer (*out of head*)?
H. Taal // Language	
34.	E: Was his/her language development delayed, or doesn't he/she speak at all? A1: Was sy/haar taalontwikkeling vertraag of praat hy/sy glad nie? A2: Was sy/haar taalontwikkeling agterstandig of praat hy/sy glad nie? AF: Was daar 'n agterstand (*a lag in*) in sy/haar taalontwikkeling, of praat hy/sy glad nie?
35.	E1: Does he/she struggle sustaining a conversation? E2: Does he/she struggle maintaining a conversation? A1: Sukkel hy/sy om 'n gesprek te onderhou? ['*maintain' a conversation*] A2: Sukkel hy/sy om 'n gesprek te behou? A3: Sukkel hy/sy om 'n gesprek te voer? ['*have' a conversation*] AF (A1): Sukkel hy/sy om 'n gesprek te onderhou? [*was felt to have the mos appropriate carry-over of meaning]*
36.	E: Does he/she like to repeat words and expressions or does he/she use words in a way that other people find strange? A1: Hou hy/sy daarvan om woorde en uitdrukkings te herhaal of gebruik hy/sy woorde op 'n manier wat vreemd is vir ander mense? [*sentence carries direct meaning to the original*]
37.	E: Does he/she have difficulties with games of make-believe or does he/she imitate others considerably less than other children? A1: Sukkel hy/sy met speletjies van verbeelding of boots hy/sy ander aansienklik minder na as ander kinders? AF: Sukkel hy/sy met verbeelding speletjies of boots hy/sy ander aansienlik minder na as ander kinders? [*sentence carries direct meaning to the original*]
38.	E: Does he/she talk in too high a pitch or too quietly? A1: Praat hy/sy met 'n hoë toonhoogte of te sag? [*sentence carries direct meaning to the original*]
39.	E: Does he/she have difficulties keeping "on track" when telling other people something? A1: Sukkel hy/sy om "by te bly" wanneer hy/sy ander mense iets vertel? [*too direct a translation*] AF: Sukkel hy/sy om te hou by die gesprek (*stick to the conversation*) wanneer hy/sy vir ander mense iets vertel?
I. Sosiale Interaksie // Social Interaction	
40.	E1: Does he/she struggle expressing emotions and reactions with facial gestures, prosody, or body language? E2: Does he/she struggle expressing emotions and reactions with facial gestures, tone of voice, or body language? A1: Sukkel hy/sy om emosies en reaksies deur gesigsuitdrukkings, stemtoon of lyftaal uit te druk? [*sentence carries direct meaning to the original*]

41.	E: Does he/she exhibit considerable difficulties interacting with peers? A1: Lyk dit of hy/sy aansienlik sukkel om met sy/haar portuurgroep om te gaan?
42.	E: Is he/she uninterested in sharing joy, interests, and activities with others? ~~A1: Is hy/sy geïnteresseerd om geluk, belangstellings en aktiwiteite met ander te deel~~ [*exact opposite of the intended meaning*] AF: Is hy/sy nie daarin geïnteresseerd om geluk, belangstellings en aktiwiteite met ander te deel nie? [*sentence carries direct meaning to the original*]
43.	E: Can he/she only be with other people on his/her terms? A1: Kan hy/sy net by ander mense wees op sy/haar terme? AF: Kan hy/sy net by ander mense wees op sy/haar voorwaardes? [*sentence carries direct meaning to the original*]
44.	E: Does he/she have difficulties behaving as expected by peers? A1: Sukkel hy/sy om op te tree volgens wat sy/haar portuurgroep verwag?
45.	E: Do other people easily influence him/her? A1: Beïnvloed ander mense hom/haar maklik? [*sentence carries direct meaning to the original*]
J. Buigsaamheid // Flexibility	
46.	E: Does he/she get absorbed by his/her interests in such a way as being repetitive or too intense? A1: Raak hy/sy verdiep in sy/haar belangstelling op só manier dat dit herhalend of te intens is? AF: Raak hy/sy so verdiep in sy/haar belangstelling dat dit herhalend of te intens is? [*sentence carries direct meaning to the original*]
47.	E: Does he/she get absorbed by routines in such a way as to produce problems for him/herself or others? A1: Raak hy/sy op só manier opgeneem deur roetines dat dit probleme vir hom/haar of ander mense veroorsaak? AF: Raak hy/sy op só manier geabsorbeer in roetines dat dit probleme vir hom/haar of ander mense veroorsaak? [‘*geabsorbeer’ is a more direct derivation of the English term ‘absorbed’, hwoever, it is also projected to be more familiar in lower-income communities*].
48.	E: Has he/she ever engaged in strange hand movements or toe-walking when he/she was happy or upset? A1: Het hy/sy al ooit vreemde handbewegings gemaak of op sy/haar tone gestap wanneer hy/sy gelukkig of ontsteld was? [*sentence carries direct meaning to the original*]
49.	E: Does he/she get obsessed with details? A1: Raak hy/sy obsessief oor details? [*sentence carries direct meaning to the original*]
50.	E: Does he/she dislike changes in daily routines? A1: Hou hy/sy nie van veranderinge in daaglikse roetines nie? AF: Hou hy/sy nie daarvan as daaglikse roetines verander nie? [*sentence carries direct meaning to the original*]
K. Senutrekkings / ‘*Tics*’ // ‘Tics’	
51.	E: Has he/she during any period of life made involuntary sounds such as throat clearing, sneezing, swallowing, barking, or shouting? A1: Het hy/sy op enige gegewe stadium onwillekeurige geluide soos keel skoonmaak, nies, sluk, blaf of skree gemaak? [*sentence carries direct meaning to the original*]
52.	E: Has he/she during any period of life made involuntary facial grimaces or body movements?

	A1: Het hy/sy op enige gegewe stadium onwillekeurige gesiggrimas [*closest direct translation for facial grimace, but as a term was deemed overall alien*] / gesigsuitdrukking (*expressions*) of liggaamsbewegings gemaak?
	AF: Het hy/sy op enige gegewe stadium onwillekeurige trekkings in sy gesig (twitches/'pulls' in the face) of liggaamsbewegings gemaak?
53.	E: Does he/she make a lot of noise, e.g., whistle, hum, mumble? A1: Maak hy/sy baie geraas, bv. fluit, neurie of mompel? [*sentence carries direct meaning to the original*]
L. Kompulsies // Compulsions	
54.	E: Does he/she have obsessive thoughts, i.e., thoughts that recur over and over again and that he/she cannot stop, for example about dirt, contagion or that something terrible will happen? A1: Het hy/sy obsessiewe gedagtes, d.w.s. gedagtes wat oor en oor herhaal en wat hy/sy nie kan stop nie, bv. oor vuiligheid, besmetting of dat iets verskriklik sal gebeur? [*sentence carries direct meaning to the original*]
55.	E: Does he/she have compulsive behaviours such as washing his/her hands, touching things, checking on things, repeating things or procedures, arranging or ordering things, or counting? A1: Tree hy/sy kompulsief op deur byvoorbeel hande te was, goed aan te raak, goed na te gaan, goed of prosedures te herhaal, goed te rangskik of te orden, of te tel? [*sentence carries direct meaning to the original*]
M. Eetgewoontes // Eating Habits	
56.	E: Has he/she ever failed to gain enough weight for more than a year or been underweight? A1: Het hy/sy al ooit vir 'n jaar te min gewig opgetel of was hy/sy ondergewig? A2: Was hy/sy al ooit vir meer as 'n jaar ondergewig of het te min gewig opgetel? AF (A1): Het hy/sy al ooit vir meer as 'n jaar te min gewig opgetel of was hy/sy ondergewig?
57.	E: Has he/she appeared to be fearful of gaining weight or becoming fat? A1: Was hy/sy bekommerd daaroor om gewig op te tel of vet te word? [*sentence carries direct meaning to the original*]
N. Skeidings // Separations	
58.	E: Does he/she have difficulties functioning outside the family home? A1: Sukkel hy/sy om buite die gesinshuis te funksioneer? [*sentence carries direct meaning to the original*]
59.	E: Does he/she often voice fears that family members may die or get hurt? A1: Opper hy/sy dikwels vrese (*raise fears*) oor familielede wat sou kon sterf of seerkry? [*sentence carries direct meaning to the original*]
60.	E: Does he/she have an unreasonable fear of being alone or home alone? A1: Is hy/sy onredelik bang om alleen te wees of alleen by die huis te wees? [*sentence carries direct meaning to the original*]
61.	E: Does he/she have difficulty sleeping if family members are not around? A1: Sukkel hy/sy om te slaap as familielede nie daar is nie? [*sentence carries direct meaning to the original*]
62.	E: Does he/she complain about recurring headaches, bellyaches, nausea or vomiting after being separated from loved ones? A1: Kla hy/sy oor herhalende hoofpyn, maagpyn, naarheid of braking nadat hy/sy van geliefdes geskei is? [*sentence carries direct meaning to the original*]

O & P. Uittarting / Gedrag // Defiance/Conduct	
63.	E: Has there ever been a time when he/she was so angry that he/she could not be reached? A1: Was daar al ooit 'n tyd toe hy/sy só kwaad was dat hy/sy nie bereik kon word nie? AF: Was daar al ooit 'n tyd toe hy/sy só kwaad was dat jy nie tot hom/haar kon deurdring nie (*could not get through*)?
64.	E: Does he/she often argue with adults? A1: Stry hy/sy dikwels met grootmense? [*sentence carries direct meaning to the original*]
65.	E: Does he/she often tease others by deliberately doing things that are perceived as provocative? A1: Tart hy/sy dikwels ander uit deur opsetlik goed te doen wat as uitlokkend beskou word? AF: Terg hy/sy dikwels ander deur opsetlik goed te doen wat as uitlokkend beskou word? [*sentence carries direct meaning to the original*]
66.	E: Is he/she easily offended, or disturbed by others? A1: Neem hy/sy maklik aanstoot of word hy/sy maklik gesteur deur ander? [*sentence carries direct meaning to the original*]
67.	E: Is he/she easily teased? A1: Word hy/sy maklik uitgelok (*provoked*)? A2: Word hy/sy maklik geterg (*teased*)? [*implies passivity and allowing teasing to happen*] XF (A1): Word hy/sy maklik uitgelok / onstel (*provoked / upset*) [*considering this is an item assessing conduct difficulties and poor self-regulation, this was deemed to fall closer to the intended query*]
Q. Angs // Anxiety	
73.	E: Does he/she have panic attacks with sudden strong fear or anxiety? A1: Kry hy/sy paniekaanvalle na aanleiding van erge vrees of angs? AF: Kry hy/sy skielik paniekaanvalle met erge vrees en/of angs? [*sentence carries direct meaning to the original*]
74.	E: Does he/she fear leaving the house alone, being in crowds, waiting in line or going on a bus or train? A1: Is hy/sy bang om alleen die huis te verlaat, om in skares te wees, om in 'n ry te wag of om op 'n bus of 'n trein te wees? AF: Is hy/sy bang om alleen die huis te verlaat, om in skares te wees, om in 'n ry te wag of om op 'n bus of 'n trein te ry (*to ride on*)?
75.	E: Is he/she often particularly nervous or anxious? A1: Is hy/sy dikwels spesifiek senuweeagtig of angstig? AF: Is hy/sy dikwels baie (*very*) senuweeagtig of angstig?
R. Gemoedstoestand // Mood	
76.	E: Does he/she have poor self-confidence? A1: Het hy/sy swak selfvertroue? [*sentence carries direct meaning to the original*]
77.	E: Does he/she often complain about bellyaches, headaches, breathing difficulties or other bodily symptoms? A1: Kla hy/sy gereeld oor hoofpyn, maagpyn, asemhalingsprobleme of ander liggaamlike simptome? [*sentence carries direct meaning to the original*]
78.	E: Has he/she had recurrent episodes with extremely high activity levels, talkativeness & a flight/flurry of ideas?

	A1: Het hy/sy al herhaaldelike episodes met 'n uiters hoë aktiwiteitsvlak, spraaksug en "*vlug van idees*" gehad?" A2: Het hy/sy al herhaaldelike episodes van baie hoë energievlakke, praterigheid en "spring van een idee 'n ander" gehad?" A3: Het hy/sy al herhaaldelike episodes van baie hoë energievlakke en praterigheid gehad en waar hy/sy van een idee tot 'n ander spring? AF (A3): Het hy/sy al herhaaldelike episodes gehad van uiterse (*outwardly*) hoë aktiwiteitsvlakke, praterigheid en waar sy/haar gedagtes vinning van een idee na 'n ander spring (*his/her thoughts jump quickly from one idea to another*)?
79.	E: Does he/she have recurrent periods of obvious irritability? A1: Het hy/sy herhaaldelike periodes van ooglopende geïrriteerdheid? A2: Is hy/sy vir herhalende tydperke ooglopend geïrriteerd? AF (A1): Het hy/sy herhaaldelike periodes van ooglopende geïrriteerdheid? [*sentence carries direct meaning to the original*]
80.	E: Does his/her self-confidence vary considerably across different situations? A1: Wissel sy/haar selfvertroue aansienlik in verskillende situasies?
S. Werklikheidsbegrip // Concept of Reality	
81.	E: Has he/she ever had visions or seen things that no one else could see? A1: Het hy/sy al ooit visioene gehad of dinge gesien wat niemand anders kon sien nie?
T. Allerlei // Miscellaneous	
82.	E: Does he/she stutter? A1: Stotter hy/sy? AF: Hakkel hy/sy? [*sentence carries direct meaning to the original and is considered 'better' Afrikaans*]
83.	E: Is he/she or has she/she ever been bullied by other children in school? A1: Word hy/sy of is hy/sy al ooit deur ander kinders by die skool geboelie?
84.	E: Has he/she ever been severely overweight? A1: Was hy/sy al ooit erg oorgewig?
85.	E: Does he/she often have sleeping problems? A1: Het hy/sy dikwels probleme met slaap? A2: Sukkel hy/sy dikwels om te slaap?
86.	E: Does he/she often have nightmares? A1: Het hy/sy dikwels nagmerries?
87.	E: Does he/she often walk in his/her sleep or have nocturnal panic attacks when he/she cannot be "reached" or comforted? A1: Loop hy/sy dikwels in sy/haar slaap of het nagaanvalle wanneer hy/sy nie "bereik" kan word of getroos kan word nie? AF: Loop hy/sy dikwels in sy/haar slaap, of het hy/sy al wakker geword met 'n nagtelike paniek aanval en jy nie tot hom/haar kon deurdring (*cannot get through to*) of hom/haar kon vertroos nie?

APPENDIX J

A-TAC TRANSLATION: isiXHOSA WORKSHEET

All isiXhosa A-TAC Draft and Final Versions of Items

Key: X1 = Original Translation. XF = Final Version. (*X**) = (Root Version Used). XF indicates group consensus on semantic content, and not just grammatical. XD = post-group adjustments with colleagues. E1 = Original English Version. E2 = Adjusted English Version.

A. Ulawulo lweentshukumo zomzimba // Motor Control		**Rating (1-5)**
1.	E1. Does he/she have problems coordinating movements smoothly? E2: Does he/she struggle to manage movements smoothly?	
	X1: Ingaba unengxaki ngokulungelelanisa iintshukumo zakhe ngaphandle kwamagingxigingxi?	5,5,5,5,5,5
	X2: Ingaba umntwana unengxaki yokulungiselela iintshukumo kakuhle (*well*)?	
	X3: Ingaba umntwana uyasokola ukulawula iintshukumo ngendlela?	4,4,5,4,3,3
	XF (X3): Ingaba umntwana uyasokola ukulawula (*control*) ukushukumisa umzimba (*body movements*) wakhe ngendlela (*properly*)?	Consensus
B. Indlela yokubona nokuqonda izinto // Perception		
2.	E1: Does he/she seem disturbed by height differences such as in connection with climbing stairs etc? E2: Does he/she seem to have an issue with height differences, such as with climbing stairs etc.?	
	X1: Ingaba ubonakala ephazamisekile ngumahluko phakathi kokuphakama kweendawo ezinje ngokuqabela izitepsi njl njl.?	5,5,5,5,5,5
	X2: Ingaba umntwana ujongeka ephazamisekile ngumahluko wokuphakama okufana nokwenyuka kwezinyuko?	
	X3: Ingaba umntwana ujongeka enengxaki ngomahluko wobude okufana nokwenyuka izenyuko	2,2,2,2,3,3
	XF: Ingaba umntwana ujongeka ephazamisekile (*disturbed*) kwizinto ezinyukayo (*elevated items*) okanye eziphezulu (*or heights*) umz. ukunyuka izitepsi, njl njl.?	Consensus
3.	E1: Does he/she have difficulty judging distance or size? E2: Does he/she have difficulty telling how large or far away something is?	
	X1: Ingaba uyasokola ukwahlula ubungakanani bemigama nobukhulu bezinto?	5,5,5,5,5,5
	X2: Ingaba umntwana uyoyisakala ukohlula umgama okanye ubungakanani?	
	X3: Ingaba umntwana uyoyisakala ubukhulu okanye ukubakude kwezinto?	5,4,3,5,3,4
	XF (X1): Ingaba umntwana uyasokola ukwahlula ubungakanani bemigama nobukhulu bezinto? [*sentence carries direct meaning to the original*]	Consensus
4.	E1: Is he/she oversensitive to touch or tight clothing? E2: Is he/she oversensitive to being touched or to tight clothing?	
	X1: Ingaba unemvakalelo egqithisileyo ekubanjweni okanye ezimpahleni ezimqinisayo?	

	X2: Ingaba umntwana unobuthathaka obungaphezulu ekubambeni okanye kwimpahla ezimbambileyo?	
	X3: Ingaba umntwana unobuthathaka obungaphezulu ekubanjweni okanye kwimpahla embambhayo?	4,4,4,5,4,5
	XF (X3): Ingaba umntwana akathandi (*does not like*) ukubanjwa (*to be touched/held*) okanye akazithandi iimpahla ezimbambayo?	Consensus
5.	E1. Is he/she particularly sensitive to certain sounds/noise?	
	X1: Ingaba unemvakalelo egqithisileyo kwizandi/iingxolo ezithile?	5,5,4,5,5,5
	X2: Ingaba umntwana unobuthathaka ngakumbi kwizandi ezithile?	5,5,4,5,4,3
	XF: Ingaba umntwana akayiqheli (*is not used to/acclimated to*) ingxolo kunye nezandi ezithile? XD: Ingaba umntwana unobuthathaka obuthile (*notably sensitive to*) kwingxolo kunye nezandi ezithile? *('not used to' may be mistaken for simple non-familiarity, and so akayiqheli has been removed*).	Consensus
6.	E1: Is he/she particularly sensitive to certain flavours, smells, or consistencies/textures? E2: Is he/she particularly sensitive to certain flavours, smells, or the feel/texture of things like a scratchy jersey?	
	X1: Ingaba uvakalelwa ngokukodwa ziintyatyambo ezithile, amavumba okanye iimeko ezingaguquguqukiyo?	
	X2: Ingaba umntwana ubuthathaka ngakumbi kwincasa ezithile zokutya ivumbe okanye kwivumba?	5,3,5,5,3,5
	XF & XD: Ingaba umntwana unobuthathaka obuthile (*is notably sensitive to*) ngakumbi kwincasa ezithile zokutya, kwivumba okanye baxa ukuva izinto ezinjengejezi erhabaxa?	Consensus
C. Ukuzikisa ingqondo nesihoyo // Concentration and Attention		
7.	E1: Does he/she often fail to pay close attention to details or make careless mistakes in schoolwork, or other activities?	
	X1: Ingaba uvamise ukungakwazi ukunyamekela iinkcukacha okanye wenza iimpazamo ezibangelwa kukungahoyi emsebenzini wakhe wesikolo, okanye eminye imisebenzi?	
	X2: Ingaba umntwana ngexesha elininzi uyohluleka ukunikeza ngexesha lakhe kwizinto ekumele ezenzile okanye wenza impazamo ezingeyomfuneko kumsebenzi wesikolo, okanye kweminye imisebenzi	3,5,4,5,5,4
	XF: Ingaba umntwana ngexesha elininzi uyohluleka ukunikeza ngexesha lakhe kwizinto ekumele ezenzile okanye ingaba wenza impazamo ezilula (*easy mistake*) kumsebenzi awunikiweyo? XD (XF): Ingaba umntwana ngexesha elininzi uyohluleka ukunikeza ngexesha lakhe kwizinto ekumele ezenzile okanye ingaba wenza impazamo ezingeyomfuneko (*unnecessary mistake*) kwimisebenzi ayinikiweyo esikolweni, okanye eminye imisebenzi (*in assigned school work and other tasks*)?	Consensus
8.	E1: Does he/she often have difficulty keeping/sustaining attention in tasks or play activities? E2: Does he/she often struggle **staying** focused during tasks or play activities?	
	X1: Ingaba uvamise ukusokola ukugcina inyameko kwimisebenzi okanye emidlalweni?	
	X2: Ingaba umntwana ngexesha elininzi uyasokola ukunikeza ngexesha lakhe kumsebenzi awunikiweyo okanye emidlalweni / ekudlaleni?	2,4,4,5,4,4
	XF & XD: Ingaba umntwana rhoqo usokola ekugcineni, noqhubekeka (*continues to*) nojongana nomsebenzi anikwe (*tasks provided*) wona okanye emidlalweni / ekudlaleni?	Consensus

9.	E1: Does he/she often seem not to listen when spoken to directly?	
	X1: Ingaba uvamise ukubonakala engamamelanga xa kuthethwa naye ngqo?	5,5,5,5,5,5
	X2: Ingaba umntwana ujongeka engamameli xa kuthethwa kunye naye?	5,5,5,5,5,5
	XF (X1): Ingaba umntwana uvamise ukubonakala engamamelanga (*appears unresponsive*) xa kuthethwa naye nqo?	Consensus
10.	E1: Does he/she have difficulty following instructions and finishing tasks?	
	X1: Ingaba uyasokola ukulandela imiyalelo nokugqiba imisebenzi?	
	X2: Ingaba umntwana uyasokola ukulandela imigaqo okanye uyasokola ukugqiba umsebenzi awunikiweyo?	5,5,5,5,5,5
	XF (X2): Ingaba umntwana uyasokola ukulandela imigaqo (*rules*) okanye uyasokola ukugqiba umsebenzi awunikiweyo (*a provided task*)? XD (XF): Ingaba umntwana uyasokola ukulandela imiyalelo (*instructions*) okanye uyasokola ukugqiba imisebenzi ayinikiweyo (*provided tasks*)?	Consensus
11.	E1: Does he/she often have difficulty organizing tasks and activities?	
	X1: Ingaba uvamise ukusokola ukulungiselela imisebenzi?	
	X2: Ingaba umntwana usoloko esokola ukulungiselela umsebenzi awunikiweyo?	5,4,5,4,5,5
	XF (X2): Ingaba umntwana usoloko esokola ukulungiselela (*preparing*) umsebenzi awunikiweyo? XD (XF): Ingaba umntwana usoloko esokola ukulungiselela (*preparing*) imisebenzi ayinikiweyo?	Consensus
12.	E1: Does he/she often avoid tasks that require sustained mental effort/focus (such as homework)?	
	X1: Ingaba uvamise ukuyiphepha imisebenzi efuna kusetyenziswe amandla engqondo (nje ngomsebenzi wesikolo wasekhaya)?	
	X2: Ingaba umntwana usoloko eyibaleka imisebenzi ayinikiweyo efuna ukusebenzisa ukucinga, njengomsebenzi wesikolo wasekhaya?	5,5,5,5,5,5
	XF (X2): Ingaba umntwana usoloko eyibaleka imisebenzi ayinikiweyo efuna ukusebenzisa ukucinga (*to use thinking/concentration*) (njengomsebenzi wesikolo wasekhaya)?	Consensus
13.	E1: Does he/she often lose things?	
	X1: Ingaba uvamise ukulahla izinto?	
	X2: Ingaba umntwana uyazilahla izinto?	5,5,5,5,5,5
	XF & XD: Ingaba umntwana ulahlekelwa rhoqo (*often*) zizinto? [*sentence carries direct meaning to the original*]	Consensus
14.	E1: Is he/she easily distracted or disturbed? [*addition of disturbed was redundant in isiXhosa]*	
	X1: Ingaba uphazamiseka lula kwinto ayenzayo?	
	X2: Ingaba umntwana uphazamiseka lula?	3,4,5,5,5,5
	XF (X2): Ingaba umntwana uphazamiseka lula? [*sentence carries direct meaning to the original]*	Consensus
15.	E1: Is he/she often forgetful in daily activities, e.g., doing the dishes?	
	X1: Ingaba uvamise ukuba nokulibala kwimisebenzi yemihla ngemihla?	
	X2: Ingaba umntwana usoloko ewulibala umsebenzi wakhe wemihla?	3,3,3,4,3,5

	XF & XD: Ingaba umntwana usoloko ewulibala umsebenzi wakhe wemihla, umz. ukuhlamba izitya? [*sentence carries direct meaning to the original*]	Consensus
D. Ukutyhuthuza namaqondo enkuthalo // Impulsivity and Activity-levels		
16.	E1: Does he/she have difficulties keeping his/her hands and feet still or can he/she not stay seated?	
	X1: Ingaba uyasokola ukugcina izandla neenyawo zakhe endaweni enye okanye akakwazi ukuhlala phantsi azinze?	
	X2: Ingaba umntwana uyasokola ukugcina inyawo nezandla zakhe ndawoninye okanye akakwazi ukuhlala ndawonye?	5,4,4,5,5,5
	XF (X1): Ingaba umntwana uyasokola ukugcina izandla neenyawo zakhe endaweni enye okanye akakwazi ukuhlala phantsi azinze? [*sentence carries direct meaning to the original*]	Consensus
17.	E1: Does he/she get up and move about in class or in other situations when he/she is supposed to remain seated?	
	X1: Ingaba uyaphakama azulazule egumbini lokufundela okanye kwezinye iimeko apho kufaneleke ukuba ahlale phantsi azole?	
	X2: Ingaba umntwana uvele aphakame okanye ashukumane ngelixa kumele ehleli phantsi?	5,5,5,5,5,5
	XD (X2): Ingaba umntwana uvele aphakame okanye ashukume ngelixa kumele ehleli phantsi kwigumbi lokufundela okanye kwenye imeko? [*sentence carries direct meaning to the original*]	
18.	E1: Does he/she often run around or climb excessively compared to peers?	
	X1: Ingaba uvamise ukuhamba ngokubaleka okanye uthanda kakhulu ukugwencela xa kuthelekiswa noontangandini?	
	X2: Ingaba umntwana unokubaleka okanye anyuke ngokugqithisileyo kunootanga bakhe (*run or climb higher than peers*)? [*This is not the same meaning*]	5,5,5,5,5,5
	XD: Ingaba umntwana rhoqo uhlala ebaleka okanye enyuka kakhulu xa kuthelekiswa (*in comparison to*) noontanga bakhe?	
19.	E1: Does he/she have difficulty playing calmly and quietly?	
	X1: Ingaba uyasokola ukudlala ngokuzola nangokuthe cwaka?	
	X2: Ingaba umntwana uyasokola ukudlala ngokuthobekileyo nangokuthula? (*politely and quietly*)	5,5,5,5,5,5
	XD: Ingaba umntwana uyasokola ukudlala ngokuzola nangokuthula? (*calmly and quietly*)	
20.	E1: Does he/she often act as though he/she had "ants in his/her pants", i.e., unable to stay still? E2: Does he/she often act restless or agitated, i.e., unable to stay still?	
	X1: ~~Ingaba uvamise ukwenza ngathi "ulunywa ziimbovane", oko kukuthi akakwazi ukuhlala azinze~~? (idiomatic translation no longer in consideration)	
	X2: ~~Ingaba umntwana ukhe enze okungathi kunembhovane kwibhlukhwe yakhe umzl ukungahlali ngokuthuleyo~~ (idiomatic translation no longer in consideration)	2,4,4,4,4,1
	XF: Ingaba umntwana usoloko ephazamiseka lula, umz. ukungahlali ngocwangco? XD: Ingaba umntwana usoloko esenza ngokungazoli (*restlessly*) okanye ukuphazamiseka (*disturbed*) umz. ukungahlali ngokuthuleyo?	Consensus
21.	E1: Does he/she talk constantly?	
	X1: Ingaba uthetha oko	

	X2: Ingaba umntwana uthetha rhoqo (*often*)?	4,4,5,5,5,5
22.	E1: Does he/she often blurt out answers to questions before they are completed? X1: Ingaba usuke nje aqhabalake aphendule imibuzo ngaphambi kokuba ugqibe ukumbuza? X2: Ingaba usoloko ephendula imibuzo phambi kwexesha? X3: Ingaba usoloko ephendula kwimibuzo ingekagqitywa ukubuzwa?	5,5,4,5,5,5
	XF: Ingaba umntwana usoloko eqhabalaka aphendula kwimibuzo ingekagqitywa ukubuzwa? [*sentence carries direct meaning to the original*]	Consensus
23.	E1: Does he/she have difficulty waiting their turn? X1: Ingaba uyasokola ukulinda ityeli lakhe? X2: Ingaba umntwana uyasokola ukulinda ixesha lakhe? [*sentence carries direct meaning to the original*]	5,5,4,5,5,5
24.	E1: Does he/she often interrupt, or intrude on, others? X1: Ingaba uvamise ukuphazamisa abanye okanye azifake ezintweni ezingafuni yena? X2: Ingaba umntwana unokuphazamisa (*disrupt*) okanye angenelele (*intrude on*) kwabanye rhoqo?	4,5,5,5,5,4
25.	E1: Does he/she easily get bored? X1: Ingaba uyakhawuleza ukudikwa? X2: Ingaba umntwana ukhawuleza aphelelwe ngumdla (*quickly lose interest*)?	5,5,4,5,5,5
	XD (X1): Ingaba umntwana uyakhawuleza ukudikwa (easily bored)? [*sentence carries direct meaning to the original*]	
E. Ukufunda // Learning		
26.	E1: Has he/she had more difficulties than expected acquiring reading skills? X1: Ingaba umntwana uyasokola kunoko kulindelekileyo ukuphuhlisa izakhono zokufunda? [*sentence carries direct meaning to the original*]	4,4,5,5,5,5
27.	E1: Is learning slow and laborious/effortful for him/her? XF: Ingaba umntwana ukufunda kunzima (*difficult*) kwaye kuthatha ixesha (*time consuming*) kuye?	Consensus
28.	E1: Does he/she have difficulties with basic maths? X1: Ingaba umntwana uyasokola ngezibalo ezisisiseko? [*sentence carries direct meaning to the original*]	5,4,5,5,4,5
F. Izakhono zokucwangcisa kunye nezokulungiselela imisebenzi // Planning and Organizing Tasks		
29.	E1: Does he/she have difficulty shifting a plan or strategy when it is required? XF: Ingaba umntwana uyasokola ukutshintsha izicwangciso okanye amacebo xa oko kuyimfuneko? [*sentence carries direct meaning to the original*]	Consensus
30.	E1: Does he/she have difficulty keeping things in order around him/her? X1: Ingaba umntwana uyasokola ukugcina izinto ezimngqongileyo (*around them*) zimi ngocwangco? [*sentence carries direct meaning to the original*]	4,5,5,4,5,5

G. Ukukhumbula // Memory		
31.	E1: Does he/she have difficulties remembering where he/she put things? X1: Ingaba umntwana uyasokola ukukhumbula apho izinto azibeke khona? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
32.	E1: Does he/she have difficulties remembering long or multiple-step instructions? X1: Ingaba umntwana uyasokola ukukhumbula imiyalelo emide okanye enamanyathelo aliqela? [*sentence carries direct meaning to the original*]	5,5,4,5,5,4
33.	E1: Does he/she have difficulties learning rhymes, songs, multiplication tables etc by heart? X1: Ingaba uyasokola ukufunda iimfano-ziphelo, iingoma, iitafile zophinda-phindo lwamanani njl njl azigcine ngentloko?	5,2,4,5,5,5
	XF: Ingaba umntwana uyasokola ukufunda iimvano-ziphelo, iingoma, iitafile zophinda-phindo lwamanani njl. njl. azigcine ngengqondo (*out of head/memorized*)?	Consensus
H. Ulwimi // Language		
34.	E1: Was his/her language development delayed, or doesn't he/she speak at all? X1: Ingaba ukuphuhla kokuthetha kwakhe kwaye kwalibaziseka okanye akathethi konke konke? X2: Ingaba umtwana ulibazisekile ekufundeni ulwimi lwakhe, okanye akathethi kwaphela? [*sentence carries direct meaning to the original*]	4,4,5,4,4,5
35.	E1: Does he/she struggle sustaining a conversation? E2: Does he/she struggle maintaining a conversation? X1: Ingaba uyasokola ukuqhuba incoko? X2: Ingaba umntwana uyasokola ukuqhubekeka nencoko?	5,5,5,4,5,5
	XF (X2): Ingaba umntwana uyasokola ukuqhubekeka nencoko (*keep a conversation going*)?	Consensus
36.	E1: Does he/she like to repeat words and expressions or does he/she use words in a way that other people find strange? X1: Ingaba uyathanda ukuphinda-phinda amagama okanye iintetho okanye ingaba usebenzisa amagama ngendlela abanye abantu abayifumana ingaqhelekanga? X2: Ingaba umntwana uyathanda ukuphinda phinda amagama okanye ingaba amagama uwasebenzisa ngendlela engaqhelekanga ebantwini (*unusual to others*)?	5,5,5,5,5,4
37.	E1: Does he/she have difficulties with games of make-believe or does he/she imitate others considerably less than other children? X1: Ingaba uyasokola kwimidlalo esebenzisa imifanekiso-ngqondweni okanye ingaba ubalinganisa kancinci abanye kunabanye abantwana? X2: Ingaba umntwana uyasokola ngemidlalo eyenzelwe ukukholelwa okanye unokulinganisa abanye abantwana ngoluhlobo olusezantsi kunabanye	3,4,4,5,4,5
	XF (X1): Ingaba umntwana uyasokola kwimidlalo esebenzisa imifanekiso-ngqondweni (*games of imagination*) okanye ingaba ubalinganisa (*imitate*) kancinci abanye kunabanye abantwana?	Consensus
38.	E1: Does he/she talk in too high a pitch or too quietly? X1: Ingaba uthethela phezulu kakhulu okanye ezantsi kakhulu?	

	X2: Ingaba umntwana uyakhwaza (*shout*) xa ethetha okanye uthethela phantsi	5,5,5,5,5,5
	XD (X1): Ingaba umntwana uthethela ngesandi esibukhali (*in a sharp/high tone*) okanye uthethela phantsi?	
39.	E1: Does he/she have difficulties keeping "on track" when telling other people something? X1: Ingaba uyasokola ukugcina umxholo xa exelela abanye into? X2: Ingaba umntwana uyasokola ukucacisa ngendlela xa exelela abanye abantu into?	5,5,5,4,5,5
	XF (X1): Ingaba umntwana uyasokola ukugcina umxholo (*keep the topic/content*) xa exelela abanye into?	Consensus
I. Intlalo Intsebenziswano // Social Interaction		
40.	E1: Does he/she struggle expressing emotions and reactions with facial gestures, tone of voice, or body language? X1: Ingaba uyasokola ukubonakalisa iimvakalelo zakhe ngokusebenzisa inkangeleko yobuso, ithoni yelizwi, okanye ngokuthetha ngokusebenzisa umzimba? X2: Ingaba umntwana uyasokola ukubonisa uhlobo aziva ngalo ngohlobo lokutshintsha kobuso, nangendlela yokuthetha, okanye ngentshukumo yomzimbha	5,5,5,5,4,5
	XF (X2): Ingaba umntwana uyasokola ukubonisa uhlobo aziva ngalo ngohlobo lokutshintsha kobuso, nangendlela yokuthetha, okanye ngentshukumo yomzimbha? [*sentence carries direct meaning to the original*]	Consensus
41.	E1: Does he/she exhibit considerable difficulties interacting with peers? X1: Ingaba ubonakalisa ukusokola ekusebenzisaneni noontangandini? X2: Ingaba umntwana unokusokola ukuncokola kunye nabanye?	5,5,5,5,5,5
	XF: Ingaba umntwana unokusokola ukuncokola kakhulu kunye noontanga bakhe? [*sentence carries direct meaning to the original*]	Consensus
42.	E1: Is he/she uninterested in sharing joy, interests, and activities with others? X1: Ingaba akanamdla wokwabelana ngolonwabo, ngemidla yakhe, nemisebenzi kunye nabanye? X2: Ingaba umntwana akanamdla wokwabelana ngovuyo, ngomdla okanye ngemidlalo kunye nabanye? [*sentence carries direct meaning to the original*]	5,4,4,5,4,4
43.	E1: Can he/she only be with other people on his/her terms? X1: Ingaba ukwazi ukuba kunye nabanye kuphela ngokwendlela nexesha elifunwa nguye? X2: Ingaba umntwana uba kunye nabanye xa kuthande yena ?	5,5,5,5,5,5
	XF (X2): Ingaba umntwana uba kunye nabanye xa kuthande yena? (*as per his/her liking/choice*)? XD (XF): Ingaba umntwana ufuna ukuba kunye nabanye xa kuthande yena (*as per his/her liking/choice*) kuphela (*only*)?	Consensus
44.	E1: Does he/she have difficulties behaving as expected by peers? X1: Ingaba uyasokola ukuziphatha ngendlela elindelekileyo koontangandini? X2: Ingaba umntwana uyasokola ukuziphatha ngendlela abanye abalingana naye abalindele aziphathe ngayo? [*sentence carries direct meaning to the original*]	5,5,5,4,5,5

45.	E1: Do other people easily influence him/her? X1: Ingaba ulukuhleka lula ngabanye abantu? X2: Ingaba abanye abantu bayakwazi ukumjika indlela yokucinga (*change the way they think*) lula?	5,5,5,5,5,5
J. Ukumelana neemeko ngeemeko // Flexibility		
46.	E1: Does he/she get absorbed by his/her interests in such a way as being repetitive or too intense? X1: Ingaba uthabatheka kakhulu zizinto anomdla kuzo kangangokuba uyaziphinda-phinda okanye azibaxe? X2: Ingaba umntwana uyathatheka ngumdla ngendlela yokuba aphinda phinde okanye abambhelele?	3,3,3,5,4,4
	XF (X1): Ingaba umntwana uthabatheka kakhulu (*so interested*) zizinto anomdla kuzo kangangokuba uyaziphinda-phinda okanye azibaxe (*exaggerate[d extent]*)?	Consensus
47.	E1: Does he/she get absorbed by routines in such a way as to produce problems for him/herself or others? X1: Ingaba uthabatheka kakhulu yimigaqo-nkqubo yemihla ngemihla kangangokuba ude azibangele iingxaki yena buqu okanye abangele abanye abantu iingxaki? X2: Ingaba umntwana uyathatheka ngohlobo lokwenza izinto (*way of doing things*) ngendlela yokuba enze nengxaki kuye nakwabanye? X3: Ingaba umntwana uyathatheka ngendlela yokwenza izinto mihla le kangangokuba uyaziphinda phinda okanye azibaxe?	4,3,4,5,3,5
	XF (X1): Ingaba umntwana uthabatheka kakhulu yimigaqo-nkqubo yemihla [*this is a deep Xhosa term for routine that is unfamiliar*] ngemihla kangangokuba ude azibangele iingxaki yena buqu okanye abangele abanye abantu iingxaki? XD (XF): Ingaba umntwana uthabatheka kakhulu ngohlobo lokwenza izinto mihla (way of doing things daily) kangangokuba (*so much so that*) ude azibangele iingxaki yena buqu okanye abangele abanye abantu iingxaki?	Consensus
48.	E1: Has he/she ever engaged in strange hand movements or toe-walking when he/she was happy or upset? X1: Ingaba wakhe wenza iintshukumo zezandla ezingaqhelekanga okanye ukuhamba ngeenzwane xa onwabile okanye ekhathazekile? X2: Ingaba umntwana wakhe wanokushukuma kwezandla ngendlela engaqhelekanga okanye ahambe ngenzwane xa onwabile okanye equmbile?	2,4,5,4,4,5
	XF (X1): Ingaba umntwana wakhe wenza iintshukumo zezandla ezingaqhelekanga okanye ukuhamba ngeenzwane xa onwabile okanye ekhathazekile? [*sentence carries direct meaning to the original*]	Consensus
49.	E1: Does he/she get obsessed with details? X1: Ingaba uthabatheka ngokugqithisileyo ziinkcukacha? X2: Ingaba umntwana uyathatheka zincukacha? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
50.	E1: Does he/she dislike changes in daily routines? X1: Ingaba akazithandi iinguqu kwimigaqo-nkqubo yemihla ngemihla? X2: Ingaba umntwana akakuthandi utshintsho kuhlobo aqhele ukwenza ngalo?	5,5,5,5,5,5
	XD (X2): Ingaba umntwana akaluthandi utshintsho kuhlobo lokwenza izinto mihla (*way of doing*	

	things daily)?	
K. Kungaqheleki okanye ezi ngxaki ziphathelele ekuziphatheni okungaqhelekanga // 'Tics'		
51.	E1: Has he/she during any period of life made involuntary sounds such as throat clearing, sneezing, swallowing, barking, or shouting? X1: Ingaba ukhe ngalo lonke ixesha lobomi wenza izandi zokuzenzela ezinjengokucoca umqala, ukuthimla, ukugwinya, ukukhonkotha, ukukhwaza?	2,2,5,5,4,3
	XF: Ingaba umntwana ukhe ngalo lonke ixesha lobomi enze izandi zokuzenzela/ingezo njongo zakhe (*not on purpose*) ezinjengokucoca umqala, ukuthimla, ukuginya, ukukhonkotha, ukukhwaza?	Consensus
52.	E1: Has he/she during any period of life made involuntary facial grimaces or body movements? X1: Ingaba ukhe ngalo lonke ixesha lobomi wenza "facial grimaces" okanye intshukumo?	4,2,4,5,3,5
	XF & XD : Ingaba umntwana ukhe ngalo lonke ixesha lobomi adlale ngobuso ('*playing faces'*) ("facial grimaces") ingezo njongo zakhe (*not on purpose*) okanye intshukumo yomzimba, ingezo njongo zakhe (*not on purpose*)?	Consensus
53.	E1: Does he/she make a lot of noise, e.g., whistle, hum, mumble? X1: Ingaba wenza ingxolo enkulu umz. uyabetha impempe, uyagcuma?	4,2,3,5,3,2
	XF: Ingaba umntwana wenza ingxolo enkulu umz. uyabetha umlozi, uyandumzela ("humming"), uyambombozela?	Consensus
L. Izinyanzeliso // Compulsions		
54.	E1: Does he/she have obsessive thoughts, i.e., thoughts that recur over and over again and that he/she cannot stop, for example about dirt, contagion or that something terrible will happen? X1: Ingaba umntwana uneengcinga ezimfikela ngokubaxekileyo, oko kukuthi iingcinga ezenzeka oko angakwaziyo ukuzikhupha engqondweni, umzekelo iingcinga ezingobumdaka (*dirty thoughts*), ezingobubi (*evil*) okanye ezokuba ikhona into embi eza kukwenzeka?	5,5,5,5,5,5
	XD (X1): Ingaba umntwana uneengcinga ezimfikela ngokubaxekileyo, oko kukuthi iingcinga ezenzeka oko angakwaziyo ukuzikhupha engqondweni, umzekelo ubumdaka (*dirt*), usulelo (*infection*) okanye ezokuba ikhona into embi eza kukwenzeka?	
55.	E1: Does he/she have compulsive behaviours such as washing his/her hands, touching things, checking on things, repeating things or procedures, arranging or ordering things, or counting? X1: Ingaba umntwana uneendlela zokuziphatha ezinyanzelisayo ezinje ngokuhlamba izandla zakhe, ukubamba izinto, ukuhlola izinto, ukuphinda-phinda izinto okanye iinkqubo, ukulungiselela okanye ukucwangcisa izinto, okanye ukubala?	4,4,5,4,5,5
M. Imikhwa yokutya // Eating Habits		
56.	E1: Has he/she ever failed to gain enough weight for more than a year or been underweight? X1: Ingaba umntwana wayekhe akabinako ukuba nobunzima obufanelekileyo bomzimba isithuba esingaphezu konyaka okanye wancipha kakhulu ngokomzimba? [*This version is phrased around 'having or losing' a lot of weight, which is not the intention of the question*]	Consensus
	XD: Ingaba umntwana wayekhe akoyisa nobunzima obufanelekileyo bomzimba isithuba (*did not grow with the correct weight*) esingaphezu konyaka okanye ingaba wayekhe ukuba nobunzima obulula kakhulu (*had really light weight*)?	

57.	E1: Has he/she appeared to be fearful of gaining weight or becoming fat? X1: Ingaba umntwana wayekhe wabonakala esoyika ukuba nobunzima bomzimba obongezelekileyo okanye ukutyeba?	5,5,5,5,5,5
N. Ulwahlukaniso // Separations		
58.	E1: Does he/she have difficulties functioning outside the family home? X1: Ingaba umntwana uyasokola ukwenza nantoni na xa engekho ekhaya phakathi kosapho (*at home Among the family*)?	4,5,5,4,4,5
59.	E1: Does he/she often voice fears that family members may die or get hurt? X1: Ingaba umntwana ukhe avakalise (*announce/express*) uloyiko lokuba amalungu osapho angasweleka okanye onzakale?	5,5,4,5,5,5
60.	E1: Does he/she have an unreasonable fear of being alone or home alone? X1: Ingaba umntwana unoloyiko olungenasihlahla (*unfounded*) lokuba yedwa okanye ukushiyeka yedwa ekhaya?	5,5,5,5,5,5
61.	E1: Does he/she have difficulty sleeping if family members are not around? X1 & XD: Ingaba umntwana uyasokola ukulala ukuba amalungu osapho awekho? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
62.	E1: Does he/she complain about recurring headaches, bellyaches, nausea or vomiting after being separated from loved ones? X1: Ingaba umntwana uhlala ekhalaza ngentloko ebuhlungu, isisu esibuhlungu, isizaphuzaphu okanye ukugabha okuqhubekekayo emva kokwahlukaniswa nabo abathandayo? [*This sentence construction seems to apply only the vomiting is recurrent*]	4,5,5,5,5,4
	XD: Ingaba umntwana uhlala ekhalaza ngeepawu eziqhubekeka (*recurring symptoms such as*) njengentloko ebuhlungu, isisu esibuhlungu, isizaphuzaphu okanye ukugabha emva kokwahlukaniswa nabo abathandayo?	
O & P. Ukungamameli/Ukuziphatha // Defiance/Conduct		
63.	E1: Has there ever been a time when he/she was so angry that he/she could not be reached? X1: Ingaba lakhe laba khona ixesha apho wayenomsindo kakhulu kangangokuba wayengenako ukufikeleleka? X2: Ingaba lake lakhona ixesha apho wayeke wacaphuka akafumaneka?	5,5,5,5,5,5
	XF: Ingaba umntwana lakhe lakhona ixesha apho wayeke wacaphuka awakwazi ukuthetha (*cannot talk to*) naye okanye ukumthomalalisa (*or soothe*)?	Consensus
64.	E1: Does he/she often argue with adults? X1: Ingaba uvamise ukuxambulisana nabantu abadala? X2: Ingaba umntwana wake (*ever*) waxambulisana nabanatu abadala?	5,5,5,5,5,5
	XD: Ingaba umntwana waxambulisana nabanatu abadala rhoqo (*often*)? [*sentence carries direct meaning to the original*]	
65.	E1: Does he/she often tease others by deliberately doing things that are perceived as provocative? X1: Ingaba uvamise ukunxwala abanye ngokwenza izinto ezaziwa nje ngezixhokonxayo ngabom?	5,5,5,5,5,5

	X2: Ingaba umntwana usoloko egezela abanye ngamabomu esenza izinto ezenza abanye babenomsindo (*until they are angered*)?	Consensus
66.	E1: Is he/she easily offended, or disturbed by others? X1: Ingaba ukhutyekiswa okanye aphazamiseke lula ngabanye? X2: Ingaba umntwana ucapuka msinya okanye ucapukiswa (*offended*) msinya ngabanye?	5,5,5,5,5,5
67.	E1: Is he/she easily teased? X1: Ingaba unxwaleka lula? X2 & XD: Ingaba umntwana ugezeleka lula? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
Q. Ukunxuba // Anxiety		
73.	E1: Does he/she have panic attacks with sudden strong fear or anxiety? X1: Ingaba ukhe aphathwe luvalo olumandla noloyiko okanye ukunxuba okungesaquphe? X2: Ingaba umntwana ubanoxinzelelo loloyiko olungamanda?	5,5,5,5,5,5
	XF: Ingaba umntwana ukhe aphathwe luvalo olumandla (*severe anxiety*) noloyiko (*with fear*) okanye ukunxuba (*confusion*) okungesaquphe (*that is sudden*)?	Consensus
74.	E1: Does he/she fear leaving the house alone, being in crowds, waiting in line or going on a bus or train? X1: Ingaba uyakoyika ukuphuma ekhaya yedwa, ukuba phakathi kwabantu abaninzi, ukufola emigceni okanye ukuya ebhasini okanye kuloliwe? X2: Ingaba umntwana unoloyiko lokuba yedwa endlini, ukuba nabantu abaninzi, ukulinda emgceni okanye ukukhwela ibhasi no loliwe?	5,5,5,5,5,5
75.	E1: Is he/she often particularly nervous or anxious? X1: Ingaba uvamise ukuba nexhala okanye ukunxuba ngokukodwa? X2 & XD: Ingaba umntwana unoku xhalaba (*nervous/anxious*) okanye ubanoloyiko (*anxious/scared*)?	4,5,5,5,5,5
R. Isimo somoya wakhe // Mood		
76.	E1: Does he/she have poor self-confidence? X1: Ingaba unengxaki yokungabinakuzithemba? X2: Ingaba umntwana unokungazithembi (*insecure*)?	5,5,5,5,5,5
	XD (X1): Ingaba umntwana unengxaki yokungabinakuzithemba (*self-doubt*)?	
77.	E1: Does he/she often complain about bellyaches, headaches, breathing difficulties or other bodily symptoms? X1: Ingaba uvamise ukukhalaza ngesisu esibuhlungu, intloko ebuhlungu, ukuphefumla nzima okanye ezinye iimpawu ezisemzimbeni? X2: Ingaba umntwana uke akhalaze ngokuba buhlungu kwesibhono, kwentloko, ukusokola ukuphefumla okanye ezinye impawu zomzimbha? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
78.	E1: Has he/she had recurrent episodes with extremely high activity level, talkativeness & a	

	flight/flurry of ideas? X1: Ingaba ukhe wanezehlo eziqhubekekayo zokuba namaqondo enkuthalo aphezulu ngokugqithisileyo, ukuthetha kakhulu kunye nemfumba yeengcinga ngexesha elinye? X2: Ingaba umntwana kwakhe kwenzeka afunyanwe kukundweba okungaphezulu, ukuthetha kakhulu? X3: Ingaba umntwana kwakhe kwenzeka afunyanwe kukundweba okuqhubekekayo okungaphezulu, ukuthetha kakhulu noku ..	3,3,4,5,4,5
	XF: Ingaba umntwana kwakhe kwenzeka afunyanwe kukundweba okuqhubekekayo okungaphezulu, ukuthetha kakhulu noku nemfumba yeengcinga ngexesha elinye (*muddled piles of ideas at once*)?	Consensus
79.	E1: Does he/she have recurrent periods of obvious irritability? X1: Ingaba umntwana unezehlo eziqhubekekayo zokudikwa msinya okucacayo? [*appears to also imply overlap with boredom*] XD: Ingaba umntwana unezehlo eziqhubekekayo zokucaphuka msinya okucacayo (*clear irritability*)?	5,5,5,5,5,5
80.	E1: Does his/her self-confidence vary considerably across different situations? X1: Ingaba ukuzithemba kwakhe kwahluka-hluka ngokuxhomekeke kwiimeko ezahlukeneyo? X2: Ingaba umntwana ukuzithemba kwakhe kuyatshintshatshintsha ngohlobo oluhlukileyo?	4,5,4,5,5,5
	XD (X1): Ingaba ukuzithemba kwakhe kwahluka-hluka ngokuxhomekeke kwiimeko ezahlukeneyo? [*sentence carries direct meaning to the original*]	
S. Indlela abona ngayo izinto ezikhoyo // Concept of Reality		
81.	E1: Has he/she ever had visions or seen things that no one else could see? X1: Ingaba umntwana wayekhe wanemibono okanye abone izinto ezingabonwayo ngabanye abantu? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
T. Ukwahluka // Miscellaneous		
82.	E1: Does he/she stutter? X1: Ingaba uyathintitha? X2: Ingaba umntwana uyathintitha? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
83.	E1: Is he/she or has she/she ever been bullied by other children in school? X1: Ingaba wayekhe waxhatshazwa ngabanye abantwana esikolweni? X2: Ingaba umntwana uke waphatheke kakubi ngabanye abantwana esikolweni? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
84.	E1: Has he/she ever been severely overweight? X1: Ingaba wayekhe wanobunzima bomzimba obukhulu ngokugqithisileyo? X2: Ingaba umntwana wakhe wanomzimbha omkhulu? [*this version does not contain the concept of 'ever been', and more crassly implies having a 'fat body'*]	5,5,5,5,5,5
	XD (X1): Ingaba umntwana wayekhe wanobunzima bomzimba obukhulu ngokugqithisileyo? [*sentence carries direct meaning to the original*]	

85.	E1: Does he/she often have sleeping problems? X1: Ingaba uvamise ukuba neengxaki ngokulala? X2: Ingaba umntwana unengxaki yokulala? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
86.	E1: Does he/she often have nightmares? X1: Ingaba uvamise ukuba namaphupha amabi? X2: Ingaba umntwana ubanawo amaphupha amabi? [*sentence carries direct meaning to the original*]	5,5,5,5,5,5
87.	E1: Does he/she often walk in his/her sleep or have nocturnal panic attacks when he/she cannot be ”reached” or comforted? X1: Ingaba uvamise ukuhamba elele okanye afikelwe ngamaphupho amabi oyike esebuthongweni kude kube nzima nokumvusa? X2: Ingaba umntwana uhamba elele okanye afumane uxinzelelo xa engathuthuzelekiyo? X3: Ingaba umntwana uhamba elele okanye afumane uxinzelelo okanye akathomalaliseki	5,3,5,5,5,3
	XF: Ingaba umntwana uhamba elele okanye afumane uxinzelelo olungathomalalisekiyo? XD (XF): Ingaba umntwana uhamba elele okanye unoloyiko afumane uxinzelelo, kangangokuba (*so much so that*) ungakwazi ukuthetha naye (*you cannot speak with him/her*) okanye ukumthomalaliseka ebusuku (*in the evening*)? [*this version was adapted to be more congruent with the translation of “reaching” the child used in question 63, and re-emphasise the context of this occurring in the evening*]	Consensus

APPENDIX K

FINAL COMBINED A-TAC VERSION

The below tables represent all language versions presented simultaneously. For actual practice, they could be separated out into different versions. Considering many healthcare practitioners do not speak isiXhosa, it is the researcher's recommendation that the English and isiXhosa versions be presented together. For every section, the versions are presented: English, isiXhosa, Afrikaans.

Child & adolescent version : Inguqulelo yabantwana abaselula nabo bafikisayo : Kinder- en adolessenteweergawe

This questionnaire is in particular detail focused on a number of abilities and behaviours in children. All children are different from one another. This means that their abilities in various areas as well as their conduct and behaviour vary a great deal. To gain as complete a picture as possible of your child, we ask you to answer a considerable number of questions. Naturally, children function in different ways at different ages. State your perception of your child's functioning as compared to his or her peers. If your child has had a certain problem or specific characteristic during any period of life, answer the question with "Yes" even if the problem or characteristic is no longer present. If a statement is untrue for your child (even if just because the child is too young for it to apply), please mark "No".

Olu luhlu lwemibuzo lugxile ngokukodwa kwinani lezakhono neendlela zokuziphatha zabantwana. Bonke abantwana bhlukile omnye komnye. Oku kuthetha ukuba izakhono zabo kwimimandla eyahlukeneyo kwakunye neendlela zabo zokuziphatha zahluka-hluka kakhulu. Ukuze sibe nomfanekiso ngqondweni opheleleyo kangangoko ngomntwana wakho, sicela ukuba uphendule inani elivisayo lemibuzo. Ngokuqhelekileyo, abantwana benza izinto ngokwahlukeneyo kwiminyaka yobudala eyahlukeneyo. Chaza imbono yakho malunga nendlela umntwana wakho enza ngayo izinto xa oko kuthelekiswa noontangabakhe. Ukuba umntwana wakho unengxaki ethile okanye uphawu oluthile ngalo naliphi na ithuba ebomini, phendula lo mbuzo ngo"ewe" nkqu nokuba umntwana uba mkhulu kwingxaki leyo okanye uphawu ngeli xesha. Ukuba umbuzo akubi nonyaniso ngomntwana wakho (nokuba umntwana wakho usemncinci kakhulu nje ngoku ukukwazi imiphendulo), nceda phendula lo mbuzo ngo"hayi" nkqu.

Hierdie vraelys is in spesifieke detail gefokus op 'n aantal vermoëns en optredes in kinders. Alle kinders verskil van mekaar. Dit beteken dat hulle vermoëns op verskeie gebiede asook hul gedrag in 'n groot mate verskil. Om so volledig moontlike oorsig van jou kind te kry, vra ons u om 'n groot getal {aantal} vrae te beantwoord. Uit die aard van die saak funksioneer kinders op verskillende maniere op verskillende ouderdomme. Vergelyk u persepsie van u kind se funksionering met sy/haar portuurgroep. As u kind 'n spesifieke probleem of spesifieke karaktereienskap gedurende enige lewenstydperk getoon het, beantwoord die vraag met "ja" selfs al is die probleem of karaktereienskap nie meer teenwoordig nie. As 'n verklaring vir u kind nie waar is nie (al is dit net omdat die kind te jonk is om van toepassing te wees), beantwoord dan met "Nee".

Child/Youth's Name	Male / Female
Naam van Jongeling	Seun / Meisie
Igama Lomntu Omtsha	Yinkwenkwe / Yintombazana
Date of Birth	Age .....
Geboortedatum	Ouderdom
Umhla wokuzalwa	Iminyaka yobudala
Form Completed By	Date: .....
Vorm Voltooi Deur	Datum:
Umntu ophendula imibuzo	Umhla:

Informant's relation to the child/youth (e.g., mother, etc) .....

Ubudlelwane bomazisi nomntwana/nomntu omtsha (oko kuthi, umama, utata, njl. njl.):
Informant se verhouding met die kind (bv. ma, ens.)

A. Motor Control **Ulawulo lweentshukumo zomzimba** **Motoriese beheer**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
1.	Does he/she struggle to manage movements smoothly? Ingaba umntwana uyasokola ukulawula ukushukumisa umzimba wakhe ngendlela? Ondervind hy/sy probleme om bewegings egalig uit te voer?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
A5	Have the peculiarities or problems relating to motor control caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kulawulo lweentshukumo zomzimba zithe zabangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met motoriese beheer gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
A6	Do the peculiarities or problems relating to motor control cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kulawulo lweentshukumo zomzimba zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met motoriese beheer gelei tot beduidende lyding vir die kind?	☐	☐	☐
A7	At what age did the peculiarities or problems relating to motor control commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kulawulo lweentshukumo zomzimba? Op watter ouderdom het die vreemdheid of probleme in verband met motoriese beheer begin?	Age: Iminyaka: Ouderdom:		
A8	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

B. Perception **Indlela yokubona nokuqonda izinto** **Persepsie**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**

2.	Does he/she seem to have an issue with height differences, such as with climbing stairs etc.? Ingaba umntwana ujongeka ephazamisekile kwizinto ezinyukayo okanye eziphezulu umz. ukunyuka izitepsi, njl njl.? Lyk dit asof hy/sy 'n probleem het met hoogteverskille bv om trappe te klim ens.?	☐	☐	☐
3.	Does he/she have difficulty judging distance or size? Ingaba umntwana uyasokola ukwahlula ubungakanani bemigama nobukhulu bezinto? Sukkel hy/sy om afstand of grootte te skat?	☐	☐	☐
4.	Is he/she oversensitive to being touched or to tight clothing? Ingaba umntwana akathandi ukubanjwa okanye akazithandi iimpahla ezimbambayo? Is hy/sy oorsensitief vir aanraking deur ander mense of stywe klere?	☐	☐	☐
5.	Is he/she particularly sensitive to certain sounds/noise? Ingaba umntwana unobuthathaka obuthile kwingxolo kunye nezandi ezithile? Is hy/sy veral sensitief vir sekere klanke/geraas?	☐	☐	☐
6.	Is he/she particularly sensitive to certain flavours, smells, or the feel/texture of things like a scratchy jersey? Ingaba umntwana unobuthathaka obuthile ngakumbi kwincasa ezithile zokutya, kwivumba okanye baxa ukuva izinto ezinjengejezi erhabaxa? Is hy/sy veral sensitief vir sekere geure, reuke of teksture soos 'n trui wat krap?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
B6	Have the peculiarities or problems relating to perception caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekuqondeni izinto zithe zabangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met persepsie gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
B7	Do the peculiarities or problems relating to perception cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekuqondeni izinto zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met persepsie gelei tot beduidende lyding vir die kind?	☐	☐	☐
B8	At what age did the peculiarities or problems relating to perception commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekuqondeni izinto? Op watter ouderdom het die vreemdheid of probleme in verband met persepsie begin?	Age: Iminyaka: Ouderdom:		
B9	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

C. Concentration and Attention **Ukuzikisa ingqondo nesihoyo** **Konsentrasie en Aandag**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**

	Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**			
7.	Does he/she often fail to pay close attention to details or make careless mistakes in schoolwork, or other activities? Ingaba umntwana ngexesha elininzi uyohluleka ukunikeza ngexesha lakhe kwizinto ekumele ezenzile okanye ingaba wenza impazamo ezingeyomfuneko kwimisebenzi ayinikiweyo esikolweni, okanye eminye imisebenzi? Versuim hy/sy gereeld om fyn op te let na besonderhede of maak hy/sy agterlosige foute in skoolwerk, of ander aktiwiteite?	☐	☐	☐
8.	Does he/she often have difficulty keeping/sustaining attention in tasks or play activities? Ingaba umntwana rhoqo usokola ekugcineni, noqhubekeka nojongana nomsebenzi anikwe wona okanye emidlalweni / ekudlaleni? Sukkel hy/sy dikwels om aandag te behou in opdragte of speelaktiwiteite?	☐	☐	☐
9.	Does he/she often seem not to listen when spoken to directly? Ingaba umntwana uvamise ukubonakala engamamelanga xa kuthethwa naye nqo? Lyk dit dikwels of hy/sy nie luister wanneer daar direk met hom/haar gepraat word nie?	☐	☐	☐
10.	Does he/she have difficulty following instructions and finishing tasks? Ingaba umntwana uyasokola ukulandela imiyalelo okanye uyasokola ukugqiba imisebenzi ayinikiweyo? Sukkel hy/sy met instruksies volg en om take te voltooi?	☐	☐	☐
11.	Does he/she often have difficulty organizing tasks and activities? Ingaba umntwana usoloko esokola ukulungiselela imisebenzi ayinikiweyo? Sukkel hy/sy met die organisering van take en aktiwiteite?	☐	☐	☐
12.	Does he/she often avoid tasks that require sustained mental effort/focus (such as homework)? Ingaba umntwana usoloko eyibaleka imisebenzi ayinikiweyo efuna ukusebenzisa ukucinga (njengomsebenzi wesikolo wasekhaya)? Vermy hy/sy dikwels take wat volgehoue fokus verg (bv. huiswerk)?	☐	☐	☐
13.	Does he/she often lose things? Ingaba umntwana ulahlekelwa rhoqo zizinto? Verloor hy/sy dikwels items?	☐	☐	☐
14.	Is he/she easily distracted or disturbed? Ingaba umntwana uphazamiseka lula? Word sy/haar aandag maklik afgelei of word hy/sy maklik gesteur	☐	☐	☐
15.	Is he/she often forgetful in daily activities, e.g., doing the dishes? Ingaba umntwana usoloko ewulibala umsebenzi wakhe wemihla, umz. ukuhlamba izitya? Is hy/sy dikwels vergeetagtig tydens daaglikse aktiwiteite, bv. om skottelgoed te was?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
C3	Have the peculiarities or problems relating to concentration and attention caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekunyamekeleni nasekuzikiseni ingqondo zithe zabangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met konsentrasie en aandag gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
C4	Do the peculiarities or problems relating to concentration and attention cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekunyamekeleni nasekuzikiseni ingqondo zimbangela ukusokola okubonakalayo?	☐	☐	☐

	Het die vreemdheid of probleme in verband met konsentrasie en aandag gelei tot beduidende lyding vir die kind?			
C5	At what age did the peculiarities or problems relating to concentration and attention commence? Ingaba kuimqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekunyamekeleni nasekuzikiseni ingqondo? Op watter ouderdom het die vreemdheid of probleme in verband met konsentrasie en aandag begin?	Age: Iminyaka: Ouderdom:		
C6	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

D. Impulsivity and Activity-levels **Ukutyhuthuza namaqondo enkuthalo** **Impulsiwiteit en aktiwiteitsvlakke**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
16.	Does he/she have difficulties keeping his/her hands and feet still or can he/she not stay seated? Ingaba umntwana uyasokola ukugcina izandla neenyawo zakhe endaweni enye okanye akakwazi ukuhlala phantsi azinze? Sukkel hy/sy om sy/haar hande en voete stil te hou of kan hy/sy nie annhou bly sit nie?	☐	☐	☐
17.	Does he/she get up and move about in class or in other situations when he/she is supposed to remain seated? Ingaba umntwana uvele aphakame okanye ashukume ngelixa kumele ehleli phantsi kwigumbi lokufundela okanye kwenye imeko? Staan hy/sy op en beweeg rond in die klas of tydens enige ander situasie wanneer hy/sy moet bly sit?	☐	☐	☐
18.	Does he/she often run around or climb excessively compared to peers? Ingaba umntwana rhoqo uhlala ebaleka okanye enyuka kakhulu xa kuthelekiswa noontanga bakhe? Hardloop hy/sy baie rond of klim oormatig baie in vergelyking met sy/haar portuurgroep?	☐	☐	☐
19.	Does he/she have difficulty playing calmly and quietly? Ingaba umntwana uyasokola ukudlala ngokuzola nangokuthula? Sukkel hy/sy om rustig en stil te speel?	☐	☐	☐
20.	Does he/she often act as though he/she had "ants in his/her pants", i.e., unable to stay still? // Does he/she often act restless or agitated, i.e., unable to stay still? Ingaba umntwana usoloko esenza ngokungazoli okanye ukuphazamiseka umz. ukungahlali ngokuthuleyo Tree hy/sy gereeld op asof hy/sy "rooi miere" het, d.w.s. is nie in staat om stil te sit nie?	☐	☐	☐
21.	Does he/she talk constantly? Ingaba umntwana uthetha rhoqo? Praat hy/sy aanhoudend?	☐	☐	☐
22.	Does he/she often blurt out answers to questions before they are completed? Ingaba umntwana usoloko eqhabalaka aphendula kwimibuzo ingekagqitywa ukubuzwa? Skree hy/sy dikwels antwoorde op vrae uit voor die vrae klaar gevra is?	☐	☐	☐
23.	Does he/she have difficulty waiting their turn?	☐	☐	☐

	Ingaba umntwana uyasokola ukulinda ixesha lakhe? Sukkel hy/sy om vir sy/haar beurt te wag?			
24.	Does he/she often interrupt, or intrude on, others? Ingaba umntwana unokuphazamisa okanye angenelele kwabanye rhoqo? Val hy/sy dikwels ander in die rede, of pla/hinder hy/sy dikwels ander?	☐	☐	☐
25.	Does he/she easily get bored? Ingaba umntwana uyakhawuleza ukudikwa? Raak hy/sy maklik verveeld?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
D2	Have the peculiarities or problems relating to impulsivity and activity caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyhuthuzeni nasekudlamkeni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met impulsiwiteit en aktiwiteitsvlakke gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
D3	Do the peculiarities or problems relating to impulsivity and activity cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyhuthuzeni nasekudlamkeni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met impulsiwiteit en aktiwiteitsvlakke gelei tot beduidende lyding vir die kind?	☐	☐	☐
D4	At what age did the peculiarities or problems relating to impulsivity and activity commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyhuthuzeni nasekudlamkeni? Op watter ouderdom het die vreemdheid of probleme in verband met impulsiwiteit en aktiwiteitsvlakke begin?	Age: Iminyaka: Ouderdom:		
D5	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

E. Learning **Ukufunda** **Leer**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
26.	Has he/she had more difficulties than expected acquiring reading skills? Ingaba umntwana uyasokola kunoko kulindelekileyo ukuphuhlisa izakhono zokufunda? Het hy/sy meer gesukkel as verwag om leesvaardighede aan te leer?	☐	☐	☐
27.	Is learning slow and laborious/effortful for him/her? Ingaba umntwana ukufunda kunzima kwaye kuthatha ixesha kuye? Leer hy/sy stadig en moeisaam?	☐	☐	☐
28.	Does he/she have difficulties with basic maths? Ingaba umntwana uyasokola ngezibalo ezisisiseko?	☐	☐	☐

	Sukkel hy/sy met basiese wiskunde?			
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
E7	Have the peculiarities or problems relating to learning caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekufundeni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met leer gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
E8	Do the peculiarities or problems relating to learning cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekufundeni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met leer gelei tot beduidende lyding vir die kind?	☐	☐	☐
E9	At what age did the peculiarities or problems relating to learning commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekufundeni? Op watter ouderdom het die vreemdheid of probleme in verband met leer begin?	Age: Iminyaka: Ouderdom:		
E10	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

F. Planning and Organizing Tasks **Izakhono zokucwangcisa kunye nezokulungiselela imisebenzi** **Beplanning en organisering van take**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
29.	Does he/she have difficulty shifting a plan or strategy when it is required? Ingaba umntwana uyasokola ukutshintsha izicwangciso okanye amacebo xa oko kuyimfuneko? Sukkel hy/sy met 'n verandering van plan of strategie wanneer dit nodig is?	☐	☐	☐
30.	Does he/she have difficulty keeping things in order around him/her? Ingaba umntwana uyasokola ukugcina izinto ezimngqongileyo zimi ngocwangco? Sukkel hy/sy om dinge in sy/haar omgewing in orde te hou?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
F6	Have the peculiarities or problems relating to planning and organizing tasks caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekucwangciseni nasekulungiseleleni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met die beplanning en organisering van take gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
F7	Do the peculiarities or problems relating to planning and organizing tasks cause him/her Significant suffering?	☐	☐	☐

	Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekucwangciseni nasekulungiseleleni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met die beplanning en organisering van take gelei tot beduidende lyding vir die kind?			
F8	At what age did the peculiarities or problems relating to planning and organizing tasks commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekucwangciseni nasekulungiseleleni? Op watter ouderdom het die vreemdheid of probleme in verband met die beplanning en organisering van take begin?	Age: Iminyaka: Ouderdom:		
F9	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

G. Memory **Ukukhumbula** **Geheue**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
31.	Does he/she have difficulties remembering where he/she put things? Ingaba umntwana uyasokola ukukhumbula apho izinto azibeke khona? Sukkel hy/sy om te onthou waar hy/sy items gesit het?	☐	☐	☐
32.	Does he/she have difficulties remembering long or multiple-step instructions? Ingaba umntwana uyasokola ukukhumbula imiyalelo emide okanye enamanyathelo aliqela? Sukkel hy/sy om lang opdragte of instruksies met baie stappe te onthou?	☐	☐	☐
33.	Does he/she have difficulties learning rhymes, songs, multiplication tables etc by heart? Ingaba umntwana uyasokola ukufunda iimvano-ziphelo, iingoma, iitafile zophinda-phindo lwamanani njl. njl. azigcine ngengqondo? Sukkel hy/sy om rympies, liedjies, maaltafels ens. uit sy/haar kop te leer?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
G9	Have the peculiarities or problems relating to memory caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekukhumbuleni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met geheue gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
G10	Do the peculiarities or problems relating to memory cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekukhumbuleni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met geheue gelei tot beduidende lyding vir die kind?	☐	☐	☐
G11	At what age did the peculiarities or problems relating to memory commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekukhumbuleni?	Age: Iminyaka: Ouderdom:		

	Op watter ouderdom het die vreemdheid of probleme in verband met geheue begin?	
G12	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee

H. Language **Ulwimi** **Taal**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
34.	Was his/her language development delayed, or doesn't he/she speak at all? Ingaba umtwana ulibazisekile ekufundeni ulwimi lwakhe, okanye akathethi kwaphela? Was daar 'n agterstand in sy/haar taalontwikkeling, of praat hy/sy glad nie?	☐	☐	☐
35.	Does he/she struggle maintaining a conversation? Ingaba umntwana uyasokola ukuqhubekeka nencoko? Sukkel hy/sy om 'n gesprek te onderhou?	☐	☐	☐
36.	Does he/she like to repeat words and expressions or does he/she use words in a way that other people find strange? Ingaba umntwana uyathanda ukuphinda phinda amagama okanye ingaba amagama uwasebenzisa ngendlela engaqhelekanga ebantwini? Hou hy/sy daarvan om woorde en uitdrukkings te herhaal of gebruik hy/sy woorde op 'n manier wat vreemd is vir ander mense?	☐	☐	☐
37.	Does he/she have difficulties with games of make-believe or does he/she imitate others considerably less than other children? Ingaba umntwana uyasokola kwimidlalo esebenzisa imifanekiso-ngqondweni okanye ingaba ubalinganisa kancinci abanye kunabanye abantwana? Sukkel hy/sy met verbeelding speletjies of boots hy/sy ander aansienlik minder na as ander kinders?	☐	☐	☐
38.	Does he/she talk in too high a pitch or too quietly? Ingaba umntwana uthethela ngesandi esibukhali okanye uthethela phantsi? Praat hy/sy met 'n hoë toonhoogte of te sag?	☐	☐	☐
39.	Does he/she have difficulties keeping "on track" when telling other people something? Ingaba umntwana uyasokola ukugcina umxholo xa exelela abanye into? Sukkel hy/sy om te hou by die gesprek wanneer hy/sy vir ander mense iets vertel?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
H10	Have the peculiarities or problems relating to language caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kulwimi zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met taal gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
H11	Do the peculiarities or problems relating to language cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kulwimi zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met taal gelei tot beduidende lyding vir die kind?	☐	☐	☐

H12	At what age did the peculiarities or problems relating to language commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kulwimi? Op watter ouderdom het die vreemdheid of probleme in verband met taal begin?	Age: Iminyaka: Ouderdom:
H13	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee

I. Social Interaction **Intlalo Intsebenziswano** **Sosiale Interaksie**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
40.	Does he/she struggle expressing emotions and reactions with facial gestures, tone of voice, or body language? Ingaba umntwana uyasokola ukubonisa uhlobo aziva ngalo ngohlobo lokutshintsha kobuso, nangendlela yokuthetha, okanye ngentshukumo yomzimbha? Sukkel hy/sy om emosies en reaksies deur gesigsuitdrukkings, stemtoon of lyftaal uit te druk?	☐	☐	☐
41.	Does he/she exhibit considerable difficulties interacting with peers? Ingaba umntwana unokusokola ukuncokola kakhulu kunye noontanga bakhe? Lyk dit of hy/sy aansienlik sukkel om met sy/haar portuurgroep om te gaan?	☐	☐	☐
42.	Is he/she uninterested in sharing joy, interests, and activities with others? Ingaba umntwana akanamdla wokwabelana ngovuyo, ngomdla okanye ngemidlalo kunye nabanye? Is hy/sy nie daarin geïnteresseerd om geluk, belangstellings en aktiwiteite met ander te deel nie?	☐	☐	☐
43.	Can he/she only be with other people on his/her terms? Ingaba umntwana ufuna ukuba kunye nabanye xa kuthande yena kuphela? Kan hy/sy net by ander mense wees op sy/haar voorwaardes?	☐	☐	☐
44.	Does he/she have difficulties behaving as expected by peers? Ingaba umntwana uyasokola ukuziphatha ngendlela abanye abalingana naye abalindele aziphathe ngayo? Sukkel hy/sy om op te tree volgens wat sy/haar portuurgroep verwag?	☐	☐	☐
45.	Do other people easily influence him/her? Ingaba abanye abantu bayakwazi ukumjika indlela yokucinga lula? Beïnvloed ander mense hom/haar maklik?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
I16	Have the peculiarities or problems relating to social interaction caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekuhlalisaneni nabantu zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met sosiale interaksie gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
I17	Do the peculiarities or problems relating to social interaction cause him/her	☐	☐	☐

	significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekuhlalisaneni nabantu zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met sosiale interaksie gelei tot beduidende lyding vir die kind?			
I18	At what age did the peculiarities or problems relating to social interaction commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekuhlalisaneni nabantu? Op watter ouderdom het die vreemdheid of probleme in verband met sosiale interaksie begin?	Age: Iminyaka: Ouderdom:		
I19	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

J. Flexibility **Ukumelana neemeko ngeemeko** **Buigsaamheid**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
46.	Does he/she get absorbed by his/her interests in such a way as being repetitive or too intense? Ingaba umntwana uthabatheka kakhulu zizinto anomdla kuzo kangangokuba uyaziphinda-phinda okanye azibaxe? Raak hy/sy so verdiep in sy/haar belangstelling dat dit herhalend of te intens is?	☐	☐	☐
47.	Does he/she get absorbed by routines in such a way as to produce problems for him/herself or others? Ingaba umntwana uthabatheka kakhulu ngohlobo lokwenza izinto mihla kangangokuba ude azibangele iingxaki yena buqu okanye abangele abanye abantu iingxaki? Raak hy/sy op só manier geabsorbeer in roetines dat dit probleme vir hom/haar of ander mense veroorsaak?	☐	☐	☐
48.	Has he/she ever engaged in strange hand movements or toe-walking when he/she was happy or upset? Ingaba umntwana wakhe wenza iintshukumo zezandla ezingaqhelekanga okanye ukuhamba ngeenzwane xa onwabile okanye ekhathazekile? Het hy/sy al ooit vreemde handbewegings gemaak of op sy/haar tone gestap wanneer hy/sy gelukkig of ontsteld was?	☐	☐	☐
49.	Does he/she get obsessed with details? Ingaba umntwana uyathatheka zincukacha? Raak hy/sy obsessief oor details	☐	☐	☐
50.	Does he/she dislike changes in daily routines? Ingaba umntwana akaluthandi utshintsho kuhlobo lokwenza izinto mihla? Hou hy/sy nie daarvan as daaglikse roetines verander nie?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
J1	Have the peculiarities or problems relating to flexibility caused significant impairment in school, among peers or at home?	☐	☐	☐

	Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele kwisakhono sokumelana neemeko ngeemeko zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met buigsaamheid gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?			
J2	Do the peculiarities or problems relating to flexibility cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele kwisakhono sokumelana neemeko ngeemeko zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met buigsaamheid gelei tot beduidende lyding vir die kind?	☐	☐	☐
J3	At what age did the peculiarities or problems relating to flexibility commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kwisakhono sokumelana neemeko ngeemeko? Op watter ouderdom het die vreemdheid of probleme in verband met buigsaamheid begin?	Age: Iminyaka: Ouderdom:		
J4	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

K. Tics **Kungaqheleki okanye ezi ngxaki ziphathelele ekuziphatheni okungaqhelekanga** **Senutrekkings / '*Tics*'**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
51.	Has he/she during any period of life made involuntary sounds such as throat clearing, sneezing, swallowing, barking, or shouting? Ingaba umntwana ukhe ngalo lonke ixesha lobomi enze izandi zokuzenzela/ingezo njongo zakhe ezinjengokucoca umqala, ukuthimla, ukuginya, ukukhonkotha, ukukhwaza? Het hy/sy op enige gegewe stadium onwillekeurige geluide soos keel skoonmaak, nies, sluk, blaf of skree gemaak?	☐	☐	☐
52.	Has he/she during any period of life made involuntary facial grimaces or body movements? Ingaba umntwana ukhe ngalo lonke ixesha lobomi adlale ngobuso ("facial grimaces") ingezo njongo zakhe okanye intshukumo yomzimba, ingezo njongo zakhe? Het hy/sy op enige gegewe stadium onwillekeurige trekkings in sy gesig of liggaamsbewegings gemaak?	☐	☐	☐
53.	Does he/she make a lot of noise, e.g., whistle, hum, mumble? Ingaba umntwana wenza ingxolo enkulu umz. uyabetha umlozi, uyandumzela ("humming"), uyambombozela? Maak hy/sy baie geraas, bv. fluit, neurie of mompel?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
K2	Have the peculiarities or problems relating to tics caused significant impairment in school, among peers or at home?	☐	☐	☐

	Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele ekuziphatheni okungaqhelekanga zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met senutrekkings gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?			
K3	Do the peculiarities or problems relating to tics cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele ekuziphatheni okungaqhelekanga zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met senutrekkings gelei tot beduidende lyding vir die kind?	☐	☐	☐
K4	At what age did the peculiarities or problems relating to tics commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekuziphatheni okungaqhelekanga? Op watter ouderdom het die vreemdheid of probleme in verband met senutrekkings begin?	Age: Iminyaka: Ouderdom:		
K5	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

L. Compulsions **Izinyanzeliso** **Kompulsies**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes**	**Yes, to some extent**	**No**
54.	Does he/she have obsessive thoughts, i.e., thoughts that recur over and over again and that he/she cannot stop, for example about dirt, contagion or that something terrible will happen? Ingaba umntwana uneengcinga ezimfikela ngokubaxekileyo, oko kukuthi iingcinga ezenzeka oko angakwaziyo ukuzikhupha engqondweni, umzekelo ubumdaka, usulelo okanye ezokuba ikhona into embi eza kukwenzeka? Het hy/sy obsessiewe gedagtes, d.w.s. gedagtes wat oor en oor herhaal en wat hy/sy nie kan stop nie, bv. oor vuiligheid, besmetting of dat iets verskriklik sal gebeur?	☐	☐	☐
55.	Does he/she have compulsive behaviours such as washing his/her hands, touching things, checking on things, repeating things or procedures, arranging or ordering things, or counting? Ingaba umntwana uneendlela zokuziphatha ezinyanzelisayo ezinje ngokuhlamba izandla zakhe, ukubamba izinto, ukuhlola izinto, ukuphinda-phinda izinto okanye iinkqubo, ukulungiselela okanye ukucwangcisa izinto, okanye ukubala? Tree hy/sy kompulsief op deur byvoorbeel hande te was, goed aan te raak, goed na te gaan, goed of prosedures te herhaal, goed te rangskik of te orden, of te tel?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
L1	Have the peculiarities or problems relating to compulsions caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele kunyanzeliso zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met kompulsies gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐

L2	Do the peculiarities or problems relating to compulsions cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kunyanzeliso zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met kompulsies gelei tot beduidende lyding vir die kind?	☐	☐	☐
L3	At what age did the peculiarities or problems relating to compulsions commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kunyanzeliso? Op watter ouderdom het die vreemdheid of probleme in verband met kompulsies begin?	Age: Iminyaka: Ouderdom:		
L4	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

M. Eating Habits **Imikhwa yokutya** **Eetgewoontes**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
56.	Has he/she ever failed to gain enough weight for more than a year or been underweight? Ingaba umntwana wayekhe akoyisa nobunzima obufanelekileyo bomzimba isithuba esingaphezu konyaka okanye ingaba wayekhe ukuba nobunzima obulula kakhulu? Het hy/sy al ooit vir meer as 'n jaar te min gewig opgetel of was hy/sy ondergewig?	☐	☐	☐
57.	Has he/she appeared to be fearful of gaining weight or becoming fat? Ingaba umntwana wayekhe wabonakala esoyika ukuba nobunzima bomzimba obongezelekileyo okanye ukutyeba? Was hy/sy bekommerd daaroor om gewig op te tel of vet te word?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
M7	Have the peculiarities or problems relating to eating habits caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyeni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met eet gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
M8	Do the peculiarities or problems relating to eating habits cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyeni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met eet gelei tot beduidende lyding vir die kind?	☐	☐	☐
M9	At what age did the peculiarities or problems relating to eating habits commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekutyeni? Op watter ouderdom het die vreemdheid of probleme in verband met eet begin?	Age: Iminyaka: Ouderdom:		
M10	Are they still present? Ingaba zisekhona nangoku?	Yes ☐ No ☐ Ewe Hayi		

	Is dit nog daar?	Ja Nee

	N. Separations **Ulwahlukaniso** **Skeidings**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
58.	Does he/she have difficulties functioning outside the family home? Ingaba umntwana uyasokola ukwenza nantoni na xa engekho ekhaya phakathi kosapho? Sukkel hy/sy om buite die gesinshuis te funksioneer?		☐	☐	☐
59.	Does he/she often voice fears that family members may die or get hurt? Ingaba umntwana ukhe avakalise uloyiko lokuba amalungu osapho angasweleka okanye onzakale? Opper hy/sy dikwels vrese oor familielede wat sou kon sterf of seerkry?		☐	☐	☐
60.	Does he/she have an unreasonable fear of being alone or home alone? Ingaba umntwana unoloyiko olungenasihlahla lokuba yedwa okanye ukushiyeka yedwa ekhaya? Is hy/sy onredelik bang om alleen te wees of alleen by die huis te wees		☐	☐	☐
61.	Does he/she have difficulty sleeping if family members are not around? Ingaba umntwana uyasokola ukulala ukuba amalungu osapho awekho? Sukkel hy/sy om te slaap as familielede nie daar is nie?		☐	☐	☐
62.	Does he/she complain about recurring headaches, bellyaches, nausea or vomiting after being separated from loved ones? Ingaba umntwana uhlala ekhalaza ngeepawu eziqhubekeka njengentloko ebuhlungu, isisu esibuhlungu, isizaphuzaphu okanye ukugabha emva kokwahlukaniswa nabo abathandayo? Kla hy/sy oor herhalende hoofpyn, maagpyn, naarheid of braking nadat hy/sy van geliefdes geskei is?		☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**				
N4	Have the peculiarities or problems relating to separation caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele kulwahlukaniso zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met skeiding gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?		☐	☐	☐
N5	Do the peculiarities or problems relating to separation cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kulwahlukaniso zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met skeiding gelei tot beduidende lyding vir die kind?		☐	☐	☐
N6	At what age did the peculiarities or problems relating to separation commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kulwahlukaniso? Op watter ouderdom het die vreemdheid of probleme in verband met skeiding begin?		Age: Iminyaka: Ouderdom:		

N7	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee

O. Defiance **Ukungamameli** **Uittarting**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
63.	Has there ever been a time when he/she was so angry that he/she could not be reached? Ingaba umntwana lakhe lakhona ixesha apho wayeke wacaphuka awakwazi ukuthetha naye okanye ukumthomalalisa? Was daar al ooit 'n tyd toe hy/sy só kwaad was dat jy nie tot hom/haar kon deurdring nie?	☐	☐	☐
64.	Does he/she often argue with adults? Ingaba umntwana waxambulisana nabanatu abadala rhoqo? Stry hy/sy dikwels met grootmense?	☐	☐	☐
65.	Does he/she often tease others by deliberately doing things that are perceived as provocative? Ingaba umntwana usoloko egezela abanye ngamabomu esenza izinto ezenza abanye babenomsindo? Terg hy/sy dikwels ander deur opsetlik goed te doen wat as uitlokkend beskou word?	☐	☐	☐
66.	Is he/she easily offended, or disturbed by others? Ingaba umntwana ucapuka msinya okanye ucapukiswa msinya ngabanye? Neem hy/sy maklik aanstoot of word hy/sy maklik gesteur deur ander?	☐	☐	☐
67.	Is he/she easily teased? Ingaba umntwana ugezeleka lula? Word hy/sy maklik uitgelok / onstel?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
OP1	Have the peculiarities or problems relating to defiance caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele ekungalawulekini / ekuziphatheni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met uittarting gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
OP2	Do the peculiarities or problems relating to defiance cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekungalawulekini / ekuziphatheni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met uittarting gelei tot beduidende lyding vir die kind?	☐	☐	☐
OP3	At what age did the peculiarities or problems relating to defiance commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekungalawulekini/ekuziphatheni? Op watter ouderdom het die vreemdheid of probleme in verband met uittarting begin?	Age: Iminyaka: Ouderdom:		
OP4	Are they still present? Ingaba zisekhona nangoku?	Yes ☐ No ☐ Ewe Hayi		

	Is dit nog daar?	Ja Nee

Q. Anxiety **Ukunxuba** **Angs**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
73.	Does he/she have panic attacks with sudden strong fear or anxiety? Ingaba umntwana ukhe aphathwe luvalo olumandla noloyiko okanye ukunxuba okungesaquphe? Kry hy/sy skielik paniekaanvalle met erge vrees en/of angs?	☐	☐	☐
74.	Does he/she fear leaving the house alone, being in crowds, waiting in line or going on a bus or train? Ingaba umntwana unoloyiko lokuba yedwa endlini, ukuba nabantu abaninzi, ukulinda emgceni okanye ukukhwela ibhasi no loliwe? Is hy/sy bang om alleen die huis te verlaat, om in skares te wees, om in 'n ry te wag of om op 'n bus of 'n trein te ry?	☐	☐	☐
75.	Is he/she often particularly nervous or anxious? Ingaba umntwana unoku xhalaba okanye ubanoloyiko? Is hy/sy dikwels baie senuweeagtig of angstig	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
Q4	Have the peculiarities or problems relating to anxiety caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele ekunxubeni zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met angs gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
Q5	Do the peculiarities or problems relating to anxiety cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekunxubeni zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met angs gelei tot beduidende lyding vir die kind?	☐	☐	☐
Q6	At what age did the peculiarities or problems relating to anxiety commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele ekunxubeni? Op watter ouderdom het die vreemdheid of probleme in verband met angs begin?	Age: Iminyaka: Ouderdom:		
Q7	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ Ewe Ja	No ☐ Hayi Nee	

R. Mood **Isimo somoya wakhe** **Gemoedstoestand**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana**	**No** **Hayi** **Nee**

	kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**		**Ja, in 'n mate**	
76.	Does he/she have poor self-confidence? Ingaba umntwana unengxaki yokungabinakuzithemba? Het hy/sy swak selfvertroue?	☐	☐	☐
77.	Does he/she often complain about bellyaches, headaches, breathing difficulties or other bodily symptoms? Ingaba umntwana uke akhalaze ngokuba buhlungu kwesibhono, kwentloko, ukusokola ukuphefumla okanye ezinye impawu zomzimbha? Kla hy/sy gereeld oor hoofpyn, maagpyn, asemhalingsprobleme of ander liggaamlike simptome?	☐	☐	☐
78.	Has he/she had recurrent episodes with extremely high activity levels, talkativeness & a flight/flurry of ideas? Ingaba umntwana kwakhe kwenzeka afunyanwe kukundweba okuqhubekekayo okungaphezulu, ukuthetha kakhulu noku nemfumba yeengcinga ngexesha elinye? Het hy/sy al herhaaldelike episodes gehad van uiterse (*outwardly*) hoë aktiwiteitsvlakke, praterigheid en waar sy/haar gedagtes vinning van een idee na 'n ander spring?	☐	☐	☐
79.	Does he/she have recurrent periods of obvious irritability? Ingaba umntwana unezehlo eziqhubekekayo zokucaphuka msinya okucacayo? Het hy/sy herhaaldelike periodes van ooglopende geïrriteerdheid?	☐	☐	☐
80.	Does his/her self-confidence vary considerably across different situations? Ingaba ukuzithemba kwakhe kwahluka-hluka ngokuxhomekeke kwiimeko ezahlukeneyo? Wissel sy/haar selfvertroue aansienlik in verskillende situasies?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
R9	Have the peculiarities or problems relating to mood caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele kwisimo sakhe sengqondo zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met sy/haar gemoedstoestand gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
R10	Do the peculiarities or problems relating to mood cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele kwisimo sakhe sengqondo zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met sy/haar gemoedstoestand gelei tot beduidende lyding vir die kind?	☐	☐	☐
R11	At what age did the peculiarities or problems relating to mood commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelele kwisimo sakhe sengqondo? Op watter ouderdom het die vreemdheid of probleme in verband met sy/haar gemoedstoestand begin?	Age: Iminyaka: Ouderdom:		
R12	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ No ☐ Ewe Hayi Ja Nee		

S. Concept of Reality **Indlela abona ngayo izinto ezikhoyo** **Werklikheidsbegrip**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
81.	Has he/she ever had visions or seen things that no one else could see? Ingaba umntwana wayekhe wanemibono okanye abone izinto ezingabonwayo ngabanye abantu? Het hy/sy al ooit visioene gehad of dinge gesien wat niemand anders kon sien nie?	☐	☐	☐
	If "Yes" or "Yes, to some extent" to this question: **Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:** **Indien "Ja" of "Ja, in 'n mate" op hierdie vrae:**			
S3	Have the peculiarities or problems relating to concept of reality caused significant impairment in school, among peers or at home? Ingaba oku kungaqheleki okanye ezi ngxaki eziphathelele ekuboneni kwakhe izinto ezikhoyo zithe zambangela ukudodobala okubonakalayo esikolweni, phakathi koontangandini okanye ekhaya? Het die vreemdheid of probleme in verband met realiteitsbegrip gelei tot beduidende verswakking in skoolprestasie, tussen portuurgroeplede of by die huis?	☐	☐	☐
S4	Do the peculiarities or problems relating to concept of reality cause him/her significant suffering? Ingaba oku kungaqheleki okanye ezi ngxaki ziphathelele ekuboneni kwakhe izinto ezikhoyo zimbangela ukusokola okubonakalayo? Het die vreemdheid of probleme in verband met realiteitsbegrip gelei tot beduidende lyding vir die kind?	☐	☐	☐
S5	At what age did the peculiarities or problems relating to concept of reality commence? Ingaba kumqale xa eneminyaka emingaphi oku kungaqheleki okanye ezi ngxaki ziphathelel ekuboneni kwakhe izinto ezikhoyo? Op watter ouderdom het die vreemdheid of probleme in verband met realiteitsbegrip begin?	Age: Iminyaka: Ouderdom:		
S6	Are they still present? Ingaba zisekhona nangoku? Is dit nog daar?	Yes ☐ Ewe Ja No ☐ Hayi Nee		

T. Miscellaneous **Ukwahluka** **Allerlei**	The essential aspect of each question is whether the problem/peculiarity has been **pronounced compared to peers during any period of life** Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe **nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi** Die hoofaspek van elke vraag is of die probleem/vreemde optrede **opvallend was in vergelyking met die portuurgroep gedurende enige gegewe lewenstydperk.**	**Yes** **Ewe** **Ja**	**Yes, to some extent** **Ewe, olo hlotyana** **Ja, in 'n mate**	**No** **Hayi** **Nee**
82.	Does he/she stutter? Ingaba umntwana uyathintitha? Hakkel hy/sy?	☐	☐	☐
83.	Is he/she or has she/she ever been bullied by other children in school?	☐	☐	☐

	Ingaba umntwana uke waphatheke kakubi ngabanye abantwana esikolweni? Word hy/sy of is hy/sy al ooit deur ander kinders by die skool geboelie?			
84.	Has he/she ever been severely overweight? Ingaba umntwana wayekhe wanobunzima bomzimba obukhulu ngokugqithisileyo? Was hy/sy al ooit erg oorgewig?	☐	☐	☐
85.	Does he/she often have sleeping problems? Ingaba umntwana unengxaki yokulala? Sukkerl hy/sy dikwels om te slaap?	☐	☐	☐
86.	Does he/she often have nightmares? Ingaba umntwana ubanawo amaphupha amabi? Het hy/sy dikwels nagmerries?	☐	☐	☐
87.	Does he/she often walk in his/her sleep or have nocturnal panic attacks when he/she cannot be “reached” or comforted? Ingaba umntwana uhamba elele okanye unoloyiko afumane uxinzelelo, kangangokuba ungakwazi ukuthetha naye okanye ukumthomalaliseka ebusuku? Loop hy/sy dikwels in sy/haar slaap, of het hy/sy al wakker geword met ‘n nagtelike paniek aanval en jy nie tot hom/haar kon deurdring of hom/haar kon vertroos nie?	☐	☐	☐

APPENDIX L

ORIGINAL PERMISSION FOR A-TAC RESEARCH

Clearance for Intellectual Property Use
Jacques Nel, MA Psych Thesis 2020

Research conducted in collaboration with the Neurodiversity Centre

PERMISSION FOR USE OF A PSYCHOMETRIC MEASURE

I, as one of the developers of the Autism – Tics, ADHD and Other Comorbidities (A-TAC) Inventory, grant permission for Mr Jacques Nel to use said neurodevelopmental screening tool, and to undertake an MA validation study of said tool for the South African context through the Neurodiversity Centre, so long as his paper and any publications stemming therefrom recognise the original developers of the tool. I further allow him to have the measures translated into the local languages necessary for his study.

Name: Prof. Chris Gillberg

Date: 27/12/2019

Email: christopher.gillberg@gu.gu.se

The Autism – Tics, ADHD and Other Comorbidities (A-TAC) Inventory was developed at Gothenburg University, Sweden, by Hansson S.L., ROJVALL A.S., Rastam, M., Gillberg C., Gillberg C., and Anckarsater, H. – first published in 2005.

APPENDIX M

PERMISSION FOR A-TAC TRANSLATION USE

Lekkerwijn Estate
Junction of R45 and R310
www.neurodiversitycentre.co.za
Groot Drakenstein

PO Box 83, Groot Drakenstein, 7680

Tel: (021) 200 8327

CLEARANCE FOR USE OF TRANSLATED STUDY SCREENS TO BE USED IN MA-RESEARCH

NEL, JACQUES (19062710)

Good day,

We trust that you are well.

The '***Autism – Tics, ADHD & Other Comorbidities***' Inventory [A-TAC] has recently been translated by the Neurodiversity Foundation – the not-for-profit service attached to the Neurodiversity Centre. This translated format is being utilised as part of the PhD research being conducted by myself (Primary Investigator): '***ESSENCE in the Breede Valley of South Africa: Towards a feasible neurodevelopmental screen for South African children***'. This and other screen translations were from English into isiXhosa and Afrikaans; and they have been adjusted based on input of the research team and colleagues.

We hereby formally grant permission for Mr Jacques Nel to use these translated versions of the A-TAC towards his Masters thesis titled: '***Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans***'.

Yours sincerely,

BEN TRUTER
DIRECTOR, NEURODIVERSITY CENTRE
Pr No **0491896**

APPENDIX N

MULTI-LINGUA SCHOOL: COLLABORATION AGREEMENT

Multi-Lingua School
isiXhosa
General, Academic, Business and Specialised

Leadership and meaningful contributions through language *Serving institutions and communities since 2005*

To whom it may concern

I, Helene Lambrechts, Founder and Director of the Multi-Lingua School, hereby indicate that I will be assisting MA candidate Jacques Nel (SU 19062710 : 9603275163089) with his dovetail study. I understand the purpose of the study, and for the involvement of the Multi-Lingua School, is to adapt and improve on an isiXhosa and Afrikaans translation of the A-TAC neurodevelopmental screen, by means of first-language speaker focus groups. I myself will act as facilitator and language bridge between the participants of the focus group and Mr Nel.

My involvement will include recruitment of potential participants through school-based associates of mine and placing them in contact with Mr Nel for final consent procedures, planning and development of protocols, active facilitation and translation during the sessions, and related functions. My services will be charged and paid privately by Mr Nel as per the budget we have agreed on below.

	Per hour	Per Unit (ZAR)	No. Units (not time)	Total (ZAR)
Facilitator: Director (Multi-Lingua) = Focus group	10	180	//	1800
Administration: letters to educators and parents	0	66.66	3	200
Venue/focus group preparation: Thinking through format and effective type of discussion, instruments to evaluate questions & let discussion flow; availability of dictionaries and other language materials to assist. Documentation and follow up if needed.	2	100	//	200

Active focus group will be conducted over 2 Saturdays, with one session for isiXhosa and Afrikaans versions of the A-TAC each. Variation or extension of my involvement will be charged at the rate I specify in discussion with Mr Nel.

Kind regards
Helene Lambechts
Director, Multi-Lingua

[Signature]

©MULTI-LINGUA SCHOOL

Skype easy. lingua multi-lingua school

Hélène Lambrechts - Language Facilitator MPhil Linguistics
Tel: 021 883 3646 Cell: 072 375 4450
E-mail: mltlanguage@gmail.com

APPENDIX O

MULTI-LINGUA SCHOOL: NON-DISCLOSURE AGREEMENT

NON-DISCLOSURE AGREEMENT

between

STELLENBOSCH UNIVERSITY
(hereinafter "the University")

And

JACQUES NEL ("the Student")

And

THE MULTI-LINGUA LANGUAGE SCHOOL (ASSISTANT)
(hereinafter "the Parties")

It is recorded that Jacques Nel is a Masters Student with the Department of Psychology, registered at the **University**. As per the MA-Thesis programme requirements, focus group data is required where the **Student** will investigate participant reception to translated screening forms and gauge their existing understanding of neurodevelopmental conditions. The **Assistant** will be assisting in collecting and translating input from the focus group participations ("the Subjects") with regard to the focus group data collection for the study "**Translating the 'Autism – Ties, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans to Ensure Conceptual Validity"** hereinafter ("the Purpose") and the **Parties** have agreed to enter into a Non-Disclosure Agreement ("the NDA") or confidentiality clauses for this Purpose.

1. In connection with the **Purpose** it will be necessary for certain Confidential Information to be provided by the **Subjects** and/or **the University** to the **Assistant**. This Confidential Information means any information disclosed to **the Parties** which has been defined as confidential in terms of the NDA;

2. The **Parties** specifically agrees not to disclose any Confidential Information to a third party and to protect it through the exercise of reasonable care. The **Parties** agrees to keep the Confidential Information in a secure environment, and not copy or use the Confidential Information except as it is reasonably necessary in connection with the **Purpose**. Access to this Confidential Information is for the sole purpose of the **Purpose** and the **Parties** agrees that breach of confidentiality may result in sanctions, civil or criminal prosecutions against the **University** or the **Parties** and/or **University** disciplinary action against the Parties.

3. The foregoing obligations shall not apply to any information which -

3.1 can be demonstrated to have been lawfully in the public domain at the time of disclosure or subsequently and lawfully becomes part of the public domain by publication or otherwise;

3.2 can be demonstrated through documentary proof to have been lawfully in the **Party's** possession prior to disclosure;

3.3 subsequently becomes available to the **Party** from a source other than the **Subjects**, which source is lawfully entitled without any restriction on disclosure to disclose such information; or

3.4 is disclosed pursuant to a requirement or request by operation of law or by any court of competent jurisdiction, provided that the **Party** gives as much notice of such impending disclosure as is reasonably possible and provide the **University** with all reasonable assistance in preventing and/or limiting such disclosure.

4. Notwithstanding the completion or non-completion of the **Purpose**, or the termination of **University's** involvement with it, this Agreement shall commence on the Signature Date and shall remain in force and effect for a period of 31/06/2022, unless replaced by another agreement concluded between the University and the Party/s superseding this Agreement.

STELLENBOSCH UNIVERSITY

Signature:

Print Name: Dr ZuhayrKafaar

Print Title: Study Departmental Supervisor

THE ASSISTANT

Signature:

Print Name: Helene Lambrechts

Print Title: Director of the Multi-Lingua Language School

THE STUDENT

Signature:

Print Name: Jacques Nel

Student Number: 1906270

APPENDIX P

STUDY BUDGET: V. 2021/04/27

This is a **self-funded study** conducted with the support of the Mulit-Lingua School Stellenbosch. Especially with regards to the School's involvement, including translation and transcription work of documents, the costs are emergent as the need for such services is called for. An agreement has been signed with the School that any additional costs not outlined below will be compensated as quoted for by the School.

	Time	Possible amount		
Operational Costs	**Per hour**	**Per Unit (ZAR)**	**No. Units (not time)**	**Total (ZAR)**
Facilitator: Director (Multi-Lingua) = Focus group	10	180	1	1800
Educators to select parents	//	100	6	600
Administration: letters to educators and parents	0	3	0	200
Phoning, data (per GB lasting 24h) if online attendance // **PPE procurement** if live attendance.	//	29	12	348
Refreshments	//	100	2	200
Venue/focus group preparation: Thinking through format and effective type of discussion, instruments to evaluate questions & let discussion flow; availability of dictionaries and other language materials to assist. Documentation and follow up if needed.	0	100	2	200
Photocopies/printing (per page)	//	0,55	176	96,8
Focus group: payment (per individual)	5	50	6	1500
Study Team Transport	//	120	4	480
Total				**5528,8**

*Each participant would earn R250 for the work group + snack and refreshment compensation. Each participants would earn an additional R100 for the focus group.

**If the translation workshop and focus group take place on the same day, a lunch break will be taken in which participants will be provided hotdogs, fruit and a drink. R400 will be budgeted in this case.

***Transcription (and related translation services) are still being quoted by the Multi Lingua School. I have agreed with the Multi Lingua School to increase the budget by the rate quoted for these services.

Additional Costs	**Per hour**	**Per Unit (ZAR)**	**No. Units (not time)**	**Cost estimate (ZAR)**
Audio Recorder Device	//	2500	1	2500

The purchase of an audio recording device is still being investigated. The Stellenbosch University IT Department has investigated the procurement of such a device on my behalf, and have provided the quotes of two suppliers for different makes. The lowest average cost is around R2500. I will investigate possible cheaper options such as Cash Crusaders and the like.

The study budget has already been demarcated and saved, and so is assured to be available for the study.

APPENDIX Q

REC ETHICAL CLEARANCE LETTER

UNIVERSITEIT STELLENBOSCH UNIVERSITY

CONDITIONAL APPROVAL GRANTED

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

26 May 2021

Project number: PSY-2021-22178

Project title: Translating the 'Autism – Tics, ADHD & Other Comorbidities' [A-TAC] Inventory into isiXhosa and Afrikaans

Dear Mr J Nel

Your REC: Social, Behavioural and Education Research (SBER) - Initial Application Form submitted on 28/04/2021 19:07 was reviewed by the REC: Social, Behavioural and Education Research (REC: SBE) on 20 May 2021 and approved with certain conditions.

This conditional approval means that the researcher may proceed with the envisaged research provided that they respond or adhere to the stipulations/conditions.

Present Committee Members:

Dr BJ Coetzee, Prof S Cornelissen, Dr HD Davis, Dr Sali Fombang, Mrs MG Fouché, Miss CJ Graham, Prof LD Hansen, Dr M Jordaan, Dr M Khoza, Dr GG Lamb, Mr B Lyu, Dr TL Maduna, Miss KM Mthelebofu, Dr GF Nel, Dr TA Nell, Mrs C Okkers, Dr MCA Oostendorp, Dr AJ Simpson, Dr I Slabbert, Mr JW Smith, Dr N Terblanche, Dr I Van Wyk, Mr A Williams, Mr HY Zaggi

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
20 May 2021	19 May 2022

REC STIPULATIONS/CONDITIONS:

1. OVERVIEW

This MA thesis aims to investigate the perceptions on translated versions of an inventory on neurodevelopment. The translated versions will be in accessible varieties of Afrikaans and isiXhosa. There are many complexities around this application that are not entirely clear. It seems that this application is part of a larger study that the applicant was the PI of. The candidate has now decided to just focus on a smaller aspect of the study for Master's degree purposes. The bigger study will be led by the applicant's supervisor.

2. PARTICIPANT SELECTION AND RECRUITMENT

Participants will be recruited through the Multiling School, whose role is not always entirely clear. It seems as if the organisation will assist in recruiting participants, lead the translation workshops and assist with transcription and translation of the inventory. The organisation will be compensated for their services. Please clarify the role of the organisation. [RESPONSE REQUIRED]

3. PROTECTION OF DATA, BOTH PAPER AND ELECTRONIC

The applicant states that the director of the Multiling School will have the audio files on her phone for transcription purposes. It would be safer if the files are shared on OneDrive. The protection of the print files (through good filing and organisation) is also not adequate. The printed files can be scanned or photographed, and a backup can be stored on OneDrive. The researcher is advised to consult with the Research ICT team at SU to find out which data transfer software may be used for the research data: https://servicedesk.sun.ac.za/jira/plugins/servlet/theme/portal/22 [RESPONSE REQUIRED]

4. ADDITIONAL COMMENTS:

The applicant states that participants will be paid R50 per hour for their time and provided with lunch. This seems inadequate. Participants should at least be compensated for transport (Taxi fare). [RESPONSE REQUIRED]

APPENDIX R

SCREEN ADAPTATION GROUP PROCEDURES

1. Group checks the clarity and register of each item. Items are to be ranked according to the perceived understandability of items, according to the below Likert scale. The scale translates to: 1) *I cannot understand at all*, 2) *It is confusing*, 3) *I sort of understand*, 4) *I mostly understand*, and 5) *I fully understand*. The schedule was as follows:
   - *Participants individually read through the questionnaire, marking off:*
     - *Whether something seems unclear, non-sensical, stiff or unnatural from the start.*
     - *Participants write down improvements or alternative wording (time allowing).*

		Andi-qondi konke konke	**Kuya-bhidisa**	**Ndibona ngathi ndiya-qonda**	**Ndiku-qonda kakuhle kakhulu**	**Ndikuve kakuhle konke**
		1	**2**	**3**	**4**	**5**
A. Ulawulo lweentshukumo zomzimba // Motor Control	Eyona nto ibalulekileyo ngombuzo ngamnye kukuba ingaba ingxaki leyo yomntwana iqaqambe/ukungaqheleki oko komntwana kuqaqambe nangaphezulu kusini na xa kuthelekiswa nemeko yoontanga bakhe kulo naliphi na inqanaba lobomi					
1.	Ingaba unengxaki ngokulungelelanisa iintshukumo zakhe ngaphandle kwamagingxigingxi? // Does he/she have problems coordinating movements smoothly? Ingaba umntwana uyasokola ukulawula iintshukumo ngendlela?					
	Ukuba uthi "Ewe" okanye uthi "Ewe, olo hlotyana" kulo mbuzo:					
A1	Ingaba ulitatasholo/uyagqwidiza xa esenza izinto? // Is he/she clumsy?					

2. Participants discuss A-TAC gate question items, and their score response are recorded, as per the above Likert scale. Consensus is constituted by the majority of participants (4/6) scoring an item 5, with no scored falling below 4. For items that already have 1+ alternate translation

versions, the most recent version is considered first. With all gate question items, preference is given to an existing unproblematic translation. The group additionally confirms that the correct meaning is being conveyed in the question:

- *Check that a question has the intended meaning.*
- *Check that the question phrasing was scored as acceptable.*
- *Eliminate these from further engagement.* This is based on consensus. If any participant feels strongly that an item is not adequate, it will be addressed in round 3. If the correct meaning is not interpreted, an item is de facto to be re-evaluated.

3. Any item that is cause for confusion or unintended interpretation is re-broached per discussion between group members, in order to seek alternatives. Preference is given to correcting core NDD-focused gate questions related to DCD, ADHD, LDs, ASD, Tics and ODD. Consensus should be reached on an item or alternate wording in order for the version to be considered final. If an item is deemed understandable, with suggestions being more idiosyncratic, then the item is to be left as is:
   - *Working as a group through the remaining questions:*
     - *What wording would need to change to make the meaning accurate?*
     - *What wording would need to change to make phrasing more comfortable?*

APPENDIX S

FULL DEPARTMENTAL PLAGIARISM DECLARATION

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

DEPARTMENT OF PSYCHOLOGY

1. I understand that plagiarism is wrong. Plagiarism is using someone else's work and pretending it is one's own.
2. I have used the American Psychological Association (APA) as the convention for citation and referencing.
3. I declare that each significant contribution to and quotation in this thesis from the work of other people has been appropriately attributed and cited and referenced.
4. I acknowledge that copying someone else's work or part of it is wrong.
5. I declare that this thesis is my own work.
6. I have not allowed and will not allow anyone to copy my work with the intention of passing it off as his or her own work.
7. I have submitted this thesis to Turnitin and have attached the report hereto.

Student name and surname: Jacques Nel

Student number: 19062710