ESSENCE IN A STRUCTURALLY DISADVANTAGED RURAL COMMUNITY IN SOUTH AFRICA

TOWARDS EFFECTIVE SCREENING OF
NEURODEVELOPMENTAL CONCERNS IN YOUNG CHILDREN

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For P, my best friend, companion and beating heart,
and for Lucas and Alex, the joy that fills my heart.

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ABSTRACT

Background: Early identification of neurodevelopmental (ND) concerns in young children is critical, with potential benefits accruing to both child and community and to public health economics. Yet the feasibility of doing so in multi-cultural, multi-lingual, structurally disadvantaged environments with highly mobile populations is not well known. ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) is a framework for understanding, conceptualizing and recognising the 'signs and symptoms' of ND differences in children. It is well-suited to foundational research in clinically under-served populations because it synthesizes symptoms across diagnostic categories rather than triaging by diagnosis, thereby enabling research into both population patterns as well as clinical presentations. **Aims**: To review existing research on screening children for neurodevelopmental problems in sub-Saharan Africa; to establish the feasibility of a two-stage screening approach using the ESSENCE framework in an under-resourced rural South African setting; to ascertain the validity of the translated ESSENCE-Q among this population; and to examine the clinical characteristics of ESSENCE among children in these pre-school settings. **Methods**: (Study I) A scoping review was conducted in accordance with the

PRISMA-ScR standards and quality assessment was conducted using the Newcastle-Ottawa Scale. (Study II) The feasibility of screening children through verbal administration of the translated ESSENCE-Q with mothers by trained lay persons, was assessed using a focus group interview with lay administrators, feedback questionnaires with participating mothers, and the research team's field notes and observations. (Study III) The validity of the ESSENCE-Q was assessed against gold standard clinical evaluations and its sensitivity and specificity calculated using different cut-off criteria. (Study IV) Descriptive statistics of assessment outcomes, with children grouped as either having received clear DSM-5 diagnoses, or identified as presenting with ND concerns requiring further assessment, or with no concern. **Results**: Limited research on screening for ND conditions in sub-Saharan Africa exist, with emerging interest in screening for a broad range of concerns simultaneously. Our screening model was found to be feasible provided certain conditions were met and pragmatic challenges accommodated. The ESSENCE-Q showed acceptable sensitivity and PPV, but low specificity and NPV, in this group. The most common clinical problems detected in this group, included delays in cognitive development, ADHD and autism. **Conclusions**: In combination, the four studies confirm that broad-based, community-embedded screening for ND concerns is possible, valuable and needed in structurally disadvantaged settings. Contextual adaptation and community involvement are crucial to screening initiatives. The ESSENCE-Q utility may be maximised when used as an entry-level screener linked to secondary evaluation. The findings support the adoption of pragmatic, inclusive screening frameworks alongside broader system strengthening to ensure that awareness translates into early, sustained developmental support.

Keywords: children; neurodevelopment; screening; sub-Saharan Africa

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SAMMANFATTNING PÅ SVENSKA

Bakgrund: Tidig identifiering av neuroutvecklingsrelaterade avvikelser hos små barn är av central betydelse och kan ge betydande vinster för både barnet, samhället och folkhälsoekonomin. Ändå är det inte klart i vilken utsträckning identifiering av sådana avvikelser är genomförbar i mångkulturella, flerspråkiga, strukturellt missgynnade miljöer med hög befolkningsrörlighet. ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) är ett ramverk för att förstå, konceptualisera och identifiera ”tecken och symtom” på neuroutvecklingsrelaterade avvikelser hos barn. Det är väl lämpat för forskning i kliniskt underförsörjda populationer eftersom det sammanfattar symtom över diagnostiska kategorier snarare än att sortera efter diagnos, vilket möjliggör forskning av både populationsmönster och kliniska presentationer.

Syfte: Att granska befintlig forskning om screening av förskolebarn för neuroutvecklingsproblem i Afrika söder om Sahara; att utvärdera genomförbarheten av en screeningmetod itvästeg med ESSENCE-ramverket i en resursfattig landsbygdsmiljö i Sydafrika; att fastställa validiteten av instrumentet ESSENCE-Q i denna population; och att undersöka kliniska karaktäristiska bland barn i dessa förskolemiljöer.

Metoder: En kartläggande litteraturöversikt genomfördes i enlighet med PRISMA-ScR riktlinjer och kvalitetsbedömningen genomfördes med hjälp av Newcastle-Ottawa-skalan (Studie I). Genomförbarheten av screening av barn genom muntlig administrering av ESSENCE-Q, utförd av utbildade lekmän, utvärderades med hjälp av fokusgruppsintervju med lekmännen som administrerade screeningen, av frågeformulär som besvarades av barnens mödrar samt forskarteamets fältanteckningar och observationer (Studie II). För att utvärdera validiteten av ESSENCE-Q jämfördes instrumentets utfall med klinisk bedömning, varpå sensitivitet och specificitet för olika gränsvärden beräknades (Studie III). Deskriptiv statistik från den kliniska bedömningen presenterades, där barnen delats in i tre grupper utifrån huruvida i) DSM-5 diagnos föreligger, ii) misstänkt neuropsykiatrisk problematik som kräver fördjupad utredning föreligger samt iii) neuroutvecklingsrelaterade svårigheter inte föreligger (Studie IV).

Resultat: Forskning om screening för neuropsykiatriska tillstånd i Afrika söder om Sahara är begränsad, även om intresset för att screena för samtidiga problem hos barn har ökat. Vår screeningmodell visade sig vara genomförbar

under förutsättning att vissa villkor uppfylldes och pragmatiska utmaningar beaktades. Sensitivitet och positivt prediktivt värde var acceptabla medan specificitet och negativt prediktivt värde var låga för ESSENCE-Q. De vanligaste kliniska problemen som upptäcktes i denna grupp var försenad kognitiv utveckling, ADHD och autism.

Slutsatser: Sammantaget bekräftar de fyra studierna att en bred, samhällsintegrerad screening för neuroutvecklingsrelaterade svårigheter är genomförbar, värdefull och nödvändig i strukturellt missgynnade miljöer. Kontextuell anpassning och lokalt samhällsengagemang är avgörande för genomförandet av screening, liksom utbildad personal och integrering av screeningen inom primärvården. ESSENCE-Q-verktyget kan används som ett screeningverktyg kopplat till sekundär klinisk bedömning. Resultat från studierna visar behovet av praktiska och tillgängliga screeningmetoder men samtidigt måste samhället bygga upp ett system i vilken tidig hjälp och stöd ges till barn med neuroutvecklingsrelaterade svårigheter.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Truter, B., Slogrove, A., Ilhan, E., Conradie, P., Thompson, L., Gillberg, C., & Billstedt, E. (2025a). Screening young children for neurodevelopmental problems in Sub-Saharan Africa: A scoping review. *BMC Psychiatry*, 25, 857.

II. Truter, B., Gillberg, C., Slogrove, A. L., Conradie, P., Billstedt, E., & Thompson, L. (2025b). Neurodevelopmental problems in pre-school children in rural Western Cape, South Africa: Is community screening feasible? *BMC Psychiatry*, 25, 348.

III. Truter, B., Gillberg, C., Thompson, L., Slogrove, A. L., Conradie, P., van der Walt, A., Lundstrom, S., & Billstedt, E. (2025c). Neurodevelopmental screening in pre-school children in a disadvantaged rural South African community using the ESSENCE-Q. *Submitted*

IV. Truter, B., Slogrove, A. L., Billstedt, E., Thompson, L., Conradie, P., van der Walt, A., & Gillberg, C. (2025d). Clinical and contextual profiles of preschoolers after community-based neurodevelopmental screening in rural South Africa. *Submitted*

CONTENTS

ABBREVIATIONS

23Q	23-Question Questionnaire
ACE	Adverse Childhood Experiences
ADHD	Attention-Deficit / Hyperactivity Disorder
ASD	Autism Spectrum Disorder
ASQ-III	Ages and Stages Questionnaires, Third Edition
ASQ-SE	Ages and Stages Questionnaires: Social-Emotional
A-TAC	Autism-Tics, ADHD and other Comorbidities Screening Questionnaire
AUDIT	WHO Alcohol Use Disorders Identification Test
BSID-III ST	Bayley Scales of Infant and Toddler Development, Third Edition, Standardized Test
DCD	Developmental Coordination Disorder
DLD	Developmental Language Disorder
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
DUDIT	WHO Drug Use Disorders Identification Test
ESSENCE	Early Symptoms and Signs Eliciting Neurodevelopmental Clinical Examinations
ESSENCE-Q	ESSENCE-Questionnaire
ECD	Early Childhood Development
GDD	Global Developmental Delay
Griffiths-III	Griffiths Scales of Child Development – 3rd Edition
HCAZ	(WHO) Head Circumference-For-Age
HREC	Human Research Ethics Committee
ICF	International Classification of Functioning, Disability and Health
IDD	Intellectual Developmental Disability

IRVT	Ingwavuma Receptive Vocabulary Test
K-SADS-PL	Kiddie Schedule for Affective Disorders and Schizophrenia, Present and Lifetime version
Little DCDQ	Little Developmental Coordination Questionnaire
LMIC	Low- and Middle-Income Countries
M-CHAT	Modified Checklist for Autism in Toddlers
ND	Neurodevelopmental
NDD	Neurodevelopmental Disorder
NDST	Neurodevelopmental Screening Tool
NPO	Non-Profit Organizations
PEDS	Parents' Evaluation of Developmental Status
PHC	Primary Health Care
RA	Research Assistant
REDCap	Research Electronic Data Capture
RPQ	Relationship Problems Questionnaire
SCQ	Social Communication Questionnaire
SDQ	Strengths and Difficulties Questionnaire
SLT	Speech and Language Therapist
SRQ	WHO 20-item Self-Reporting Questionnaire
sSA	sub-Saharan Africa
TQ	Ten Questions
WHO	World Health Organization
WHZ	Weight-for-height Z-score

1 INTRODUCTION

1.1 THE GLOBAL BURDEN OF NEURODEVELOPMENTAL CONDITIONS

The global child health agenda has shifted from a focus on children's survival to a more comprehensive commitment to enabling all children to thrive and reach their potential, as articulated in the United Nations Sustainable Development Goals (Richter et al., 2017; United Nations, 2015). Within this evolving landscape, neurodevelopmental conditions—often referred to as neurodevelopmental disorders (NDDs) and herein considered as neurodevelopmental differences—present a significant, though often under-recognised, public health concern (Gillberg, 2010; Grantham-McGregor et al., 2007). NDDs typically manifest early in development and encompass a range of problems and concerns that may be disabling or impairing across cognitive, communication, behavioural, and motor domains (Fernell & Gillberg, 2023). These include autism spectrum disorders (ASD), attention-deficit /hyperactivity disorder (ADHD), intellectual developmental disability, specific learning disorders, developmental coordination disorder (DCD), language disorders and more (Francés et al., 2022; Heady et al., 2022).

International estimates indicate that between 10% and 15% of children are affected by one or more NDDs (Bitta et al., 2017; Francés et al., 2022). These conditions frequently co-occur and are marked by overlapping features and symptoms, particularly in early childhood (Gillberg, 2010; Landgren et al., 2022). Despite this substantial burden, the epidemiological profile of NDDs in low- and middle-income countries (LMICs), including much of sub-Saharan Africa (sSA), requires considerable further scrutiny (Arora et al., 2019;

Namazzi et al., 2019; Segre et al., 2023). Large-scale population studies remain rare in sSA, and available estimates often rely on small, clinic-based samples that may under-represent rural populations and children with limited access to neurodevelopmental services (Bitta et al., 2017; Kakooza-Mwesige et al., 2014).

Several factors contribute to this limited understanding, including limited availability of contextually appropriate screening tools and constrained access to diagnostic and support services (Bitta et al., 2021; Kakooza-Mwesige et al., 2014; Marlow et al., 2019; Nel & Kafaar, 2022). Moreover, in many LMIC health systems, infectious diseases - such as HIV, tuberculosis, and malaria – have historically been prioritized over neurodevelopmental and mental health conditions (Amek et al., 2018; Bakare et al., 2014; Chanda-Kapata et al., 2022; Sarpong et al., 2022). The relative invisibility of developmental disorders within public-health surveillance frameworks has meant that epidemiological data, health-economic modelling, and workforce planning for NDDs lag far behind those for communicable or nutritional disorders (Atilola, 2017; Richter et al., 2017). Consequently, children with NDDs in these settings often remain undiagnosed and unsupported, facing lifelong implications for their education, social integration, and well-being (Atilola, 2017; Katumba et al., 2023; Tann et al., 2021).

Recent meta-analytic work has also drawn attention to regional disparities in NDD recognition, with prevalence estimates from high-income countries frequently two- to three-fold higher than those reported in LMICs - a gap likely reflecting under-detection rather than true variation (Arora et al., 2019; Bitta et al., 2017). Furthermore, recent global analyses emphasise the economic and social costs of untreated NDDs. Children whose developmental concerns are not identified early are at significant risk of experiencing poorer academic

attainment, increased healthcare use, and reduced productivity in adulthood. These inter-generational consequences underline that early developmental surveillance is not only clinically essential but a core public-health priority (Honda et al., 2023; Richter et al., 2017).

1.2 NEURODEVELOPMENTAL CONCERNS IN STRUCTURALLY DISADVANTAGED SETTINGS

The complex interplay of structural disadvantage and early life adversity in LMICs significantly heightens the risk of NDDs and complicates their identification and management (Gajwani & Minnis, 2023; Honda et al., 2023; Zarei et al., 2021). Factors including poverty, food insecurity, overcrowded living conditions, exposure to violence, inadequate stimulation, maternal mental health challenges, and perinatal exposures (e.g., to HIV or neurotoxins such as pesticides and environmental pollutants) cumulatively contribute to the 'package' of developmental risk in early childhood (Brittain et al., 2022a; Devendra et al., 2013; Knox et al., 2018; Slogrove, 2021; Stein et al., 2015). These adverse conditions not only increase the likelihood of NDDs but also may impede timely recognition and response to early signs of atypical development (Katumba et al., 2023; Turan Gurhopur, 2017; Tann et al., 2021).

Several African cohort and cross-sectional studies have illustrated how cumulative exposure to poverty, infection, and psychosocial stress contributes to delays across multiple developmental domains, particularly among preschool-age children (Bitta et al., 2021; Kakooza-Mwesige et al., 2014). Within these contexts, reduced knowledge of developmental benchmarks among caregivers and frontline health workers often leads to missed

opportunities for early detection and referral (Du Toit et al., 2021; Mazibuko & Chimbari, 2020).

Evidence demonstrates a dose–response association between cumulative childhood adversity and neurocognitive, behavioural, and emotional outcomes. When multiple risks co-occur—such as nutritional deprivation and maternal depression—their combined effect on neurodevelopment is multiplicative rather than additive (Grantham-McGregor et al., 2007; Stein et al., 2015). Understanding these interactions is critical for interpreting developmental presentations in children growing up in adversity, where cultural context influences both symptom expression and pathways to care.

While high-income countries have developed a range of specialised neurodevelopmental services, such resources are lacking in many parts of sSA (Atilola, 2017; Bakare et al., 2014; Tekola et al., 2023). In South Africa, for instance, the majority of psychiatrists work in the private sector and are concentrated in urban centres, leaving vast rural regions underserved. As of early 2024, there were reportedly fewer than 40 registered child and adolescent psychiatrists in South Africa (Lachman, 2024) with its population of over 64 million people (Statistics SA, 2024), and only one new child psychiatrist qualifying approximately every two years, (Porter, 2022). Similarly, publicly available professional listings suggest that there are approximately 15 developmental paediatricians practising in South Africa, concentrated mainly in the Western Cape and Gauteng provinces near urban centres (Medpages, 2024).

Such professional shortages mirror broader human-resource constraints across LMIC health systems, where task-sharing has become an essential strategy for extending mental-health and developmental services (Atilola, 2017; Marlow et

al., 2019). Research in South African and Kenyan communities has shown that non-specialist workers, when provided with structured tools and supervision, can reliably conduct developmental screening and identify children requiring further assessment (Bitta et al., 2021; Du Toit et al., 2021).

This scarcity underscores the importance of community-based, task-shared approaches in which trained non-specialists conduct early screening and referral. Evaluating the feasibility and accuracy of such models has become a research priority in LMIC child-development science.

Where neurodevelopmental paediatric services and specialists are present, these are almost exclusively to be found in urban centres. This layered inequity underscores the need for scalable, affordable strategies to support early identification and intervention for NDDs in under-resourced contexts (Bitta et al., 2021; Marlow et al., 2019; Tann et al., 2021).

1.3 NEURODEVELOPMENTAL SCREENING IN YOUNG CHILDREN: GLOBAL AND REGIONAL PERSPECTIVES

Early recognition of developmental concerns is essential for initiating timely support and optimising long-term outcomes (Centers for Disease Control and Prevention [CDC], 2022; Grantham-McGregor et al., 2007). Importantly, early identification should not be conflated with early diagnosis. In pre-school years, signs of NDDs are often non-specific, developmentally fluid, and overlapping across conditions, which can make precise categorical diagnosis challenging at first presentation (Landgren et al., 2022; Rah et al., 2023). Therefore, identifying deviations from expected developmental trajectories as early as feasible can enable appropriate referral and the initiation of supportive

measures, even when diagnostic boundaries remain uncertain (Richter et al., 2017; Tann et al., 2021).

The Lancet “next 1000 days” series highlights that sustained investments in early detection and nurturing-care interventions across the preschool years yield measurable gains in cognitive, social, and health outcomes, while delayed identification significantly reduces the effectiveness of intervention efforts (Draper et al., 2024). At the population level, global modelling has further estimated that large numbers of children in LMICs are at risk of not reaching their developmental potential, reinforcing the importance of systematic approaches to identifying early risk (Lu et al., 2016).

Longitudinal data from LMICs demonstrate the life-course benefits of timely support. The landmark Jamaican randomised trial of early psychosocial stimulation showed that intervention following early risk identification produced durable improvements into adulthood, including higher educational attainment and earnings (Gertler et al., 2014). Similarly, a recent JAMA Network Open trial found that a parent-guided developmental programme for very preterm and low-birth-weight infants in an LMIC context improved cognitive, language, and motor outcomes by the age of 18 months (JAMA Network Open, 2024). At a systems level, LMIC-focused reviews emphasise that structured developmental surveillance is a key entry point to care: without early identification, families miss critical periods of neuroplasticity, and health systems cannot allocate scarce intervention resources efficiently (Olusanya et al., 2021). Collectively, this growing body of literature strengthens the case for broad, transdiagnostic approaches to early developmental screening as crucial for improving long-term outcomes and advancing equity in early childhood health and development in LMICs.

Across LMICs, the importance of early detection has been highlighted in policy frameworks that link child-development outcomes to broader goals of educational attainment and human-capital formation (Atilola, 2017; Richter et al., 2017). Within this public-health lens, neurodevelopmental screening is positioned not only as a clinical process but as a foundational preventive strategy for population well-being.

Neuroscientific evidence highlights that early childhood represents a period of heightened neural plasticity, during which interventions can meaningfully alter cognitive, social, and behavioural pathways (Shonkoff et al., 2012). Failure to capitalise on this window of plasticity has long-term consequences, reinforcing inequities that begin in early childhood (Grantham-McGregor et al., 2007; Stein et al., 2015).

Screening tools play a central role in this early recognition process. Screening involves using brief, low-burden instruments to flag individuals at increased risk of a condition, warranting further assessment. In contrast, diagnostic assessment entails a more comprehensive clinical evaluation (CDC, 2022; Rah et al., 2023).

Globally, approaches to neurodevelopmental screening vary widely depending on health infrastructure, training, and cultural interpretations of child development (Marlow et al., 2019; World Health Organization [WHO], 2024;). The availability of validated, culturally appropriate screening tools remains limited across many African contexts (Abubakar et al., 2016; Bitta et al., 2017; Bitta et al., 2021). Moreover, in sub-Saharan Africa, screening is frequently carried out by healthcare workers with limited training in child development or NDDs, which further limits the utility of complex tools (Bakare et al., 2014; Du Toit et al., 2021). This capacity challenge is supported by recent evidence

from Nigeria indicating substantial gaps in primary healthcare workers' preparedness and confidence regarding autism and other NDDs, reinforcing the need for low-burden tools paired with training and supervision to support decision-making in routine services (Agbo et al., 2025).

Studies from Kenya and Uganda have demonstrated that adapted community-based screening models, when paired with simple, linguistically appropriate tools, can reach large numbers of children and achieve good sensitivity and acceptability (Bitta et al., 2021; Kakooza-Mwesige et al., 2014). However, barriers to early identification are not solely technical: they are also shaped by how families move through systems of care. Evidence from Kenya has shown that children suspected of autism may experience prolonged delays before diagnosis, often navigating multiple service contacts and relying on tertiary facilities once concerns escalate (Muthiga et al., 2025). Such findings highlight that effective screening must be embedded within workable referral routes and feedback loops that match families' real-world pathways and constraints.

While most neurodevelopmental screening instruments have been developed and validated in high-income countries, they may lack cross-cultural validity when used in LMICs. Instruments such as the Ages and Stages Questionnaire (ASQ) (Squires et al., 2009), the WHO Ten Questions (TQ) questionnaire and the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2009) require not only linguistic translation but also cultural and contextual adaptation to reflect local norms and behaviours (Durkin et al., 1995; Kakooza-Mwesige et al., 2014; Nel & Kafaar, 2022; Vorster et al., 2023). Studies such as those by Bitta et al. (2021) and Kakooza-Mwesige et al. (2014) have highlighted the necessity of evaluating the psychometric properties—including reliability, sensitivity, and specificity—of these tools in sub-Saharan African populations before they are scaled for use in population-based surveys or

clinical services. Similarly, Rah et al. (2023) emphasise the need for real-world validation of screening tools, noting that many instruments demonstrate significantly lower diagnostic accuracy outside the populations for which they were designed.

Despite these challenges, efforts to develop or adapt tools for African contexts are emerging. Locally validated instruments such as the Neurodevelopmental Screening Tool (NDST) (Bitta et al., 2021) and regionally adapted versions of the M-CHAT and Parents' Evaluation of Developmental Status (PEDS) (Glascoe, 2013) are beginning to bridge the gap (Botes et al., 2023; Vorster et al., 2021). Recent work in South Africa has demonstrated the feasibility of community-based screening approaches for preschool children using culturally adapted tools that assess multiple domains of development and behaviour, reflecting a broad-based approach to early neurodevelopmental screening. These initiatives show promising reliability and acceptability when administered by trained local workers (Botes et al., 2023; Vorster et al., 2021; Vorster et al., 2023). A similar need for locally validated, low-training-threshold tools underpinned the empirical work presented in this thesis.

Meanwhile, studies in high-risk groups—such as preterm infants in Uganda—underscore both the feasibility and importance of early neurodevelopmental surveillance within routine care settings (Nalwoga et al., 2025).

Still, the evidence base remains limited, with most studies concentrated in specific regions or populations. To strengthen early detection and support systems, large-scale studies that assess the feasibility and accuracy of broad-based screening across diverse African settings, are required. Doing so will support better estimates of NDD prevalence (Arora et al., 2019; Bitta et al., 2017; Segre et al., 2023), enable earlier intervention (Richter et al., 2017; Tann

et al., 2021), and inform health systems strengthening and policy development (Atilola, 2017; Richter et al., 2017).

In addition, beyond feasibility and psychometric evaluation, an important gap in the African literature concerns description: comparatively little is known regarding the developmental profiles and household contexts of young children identified through community screening, including the clustering of developmental concerns with caregiver strain and other adversities. This kind of evidence is necessary to design appropriate stepped-care pathways, anticipate service demand, and ensure that screening connects to realistic forms of support rather than functioning as an isolated detection activity.

The argument is therefore strong for a practically feasible, theoretically sound, inclusive screening toolset that can identify possible NDDs in children and be administered by trained health workers linked to some level of ongoing service (Bitta et al., 2021; Marlow et al., 2019).

The WHO Global Scales for Early Development (GSED) and the INTERBIO-21st Newborn and Infant Developmental Assessment (INTERBIO-NDA) provide robust, cross-culturally validated measures of early child development, but both are designed primarily for children up to around 2–3 years of age, focusing on core cognitive, motor, language, and socio-emotional milestones (Fernandes et al., 2020; Villar et al., 2021; WHO, 2023). While highly valuable for monitoring early developmental progress, they are not well suited to detecting the more complex NDDs that typically become apparent after toddlerhood. This creates a critical gap, particularly in LMICs where specialist diagnostic resources are limited.

The evidence reviewed above highlights a consistent global and regional imperative: early developmental screening must move beyond disorder-specific categorisations to encompass the full spectrum of NDDs that emerge in early childhood. Recognising that early symptoms often cut across diagnostic boundaries, and that the developmental trajectories of children are shaped by complex, interacting biological and environmental factors, there is a growing need for frameworks that can capture this multidimensional reality.

1.4 CONSIDERING EARLY DEVELOPMENTAL CONCERNS FROM A TRANSDIAGNOSTIC PERSPECTIVE

In recent years, there has been increasing consensus that early identification of NDDs requires more than disorder-specific screening. Large-scale reviews and policy analyses now emphasise the importance of assessing children's development across various domains—cognitive, communication, motor, behavioural—well before formal diagnostic endpoints are evident (Cha et al., 2024; Draper et al., 2025). This is particularly urgent in LMIC contexts, where systemised developmental surveillance is weak, yet the burden of early neurodevelopmental risk is high (Al-Haddad et al., 2025). Recognising the limitations of binary screening models, recent work proposes a 'detection'-rather-than-diagnosis paradigm in preschool children, advocating tools that cast a wide net for developmental concern, recognizing the overlapping nature of NDDs, rather than narrow criteria for a single condition (Chellapa, 2025). It is within this evolving framework that the ESSENCE concept (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) and its accompanying instrument, the ESSENCE Questionnaire (ESSENCE-Q) (Gillberg, 2012), gain relevance. This broadened global perspective is a suitable aim for approaching transdiagnostic screening for

neurodevelopmental concerns in young children in structurally disadvantaged rural South Africa.

In response to the clinical complexities inherent in early childhood presentations of NDDs, the ESSENCE framework was introduced by Christopher Gillberg approximately 17 years ago (Gillberg, 2010). ESSENCE emphasises the interconnected, overlapping, and often diagnostically ambiguous nature of early developmental symptoms and signs. It calls for a broad-based, transdiagnostic, and multidisciplinary approach to early developmental challenges, rather than narrowly targeting single diagnostic categories or emphasizing classification of one diagnosis and the exclusion of other areas of concern (Fernell & Gillberg, 2023; Gillberg, 2010).

The ESSENCE framework as a diagnostic and clinical approach is underpinned by key principles. The first, explicit in the name, is its recognition of a range of inherently multi-dimensional and overlapping signs and symptoms of early neurodevelopmental concern (Gillberg, 2010; Nygren et al., 2012). This, in turn, supports the principle of emphasising functional impact rather than a rigid set of diagnostic criteria. In practical terms, this translates to a principled call for early, holistic clinical attention, irrespective of whether a formal diagnosis can be established (Fernell & Gillberg, 2023; Richter et al., 2017). The clinical principle is then the ethical and humanistic imperative of supporting children and families as soon as concerns are raised, rather than awaiting diagnostic certainty (Richter et al., 2017).

The ESSENCE construct is increasingly cited in international child-neuropsychiatry literature as an integrative model that bridges categorical nosology and developmental neuroscience. By emphasising early detection of clusters of difficulties—rather than single-disorder screening—it provides a

theoretical scaffold for population-level approaches to child development (Gillberg et al., 2016; Landgren et al., 2022). This transdiagnostic perspective aligns closely with global shifts toward dimensional classification systems such as the Research Domain Criteria framework and the WHO's life-course model of developmental health (WHO, 2024).

These principles mirror the realities of LMIC contexts, where delayed or missed diagnoses are common and specialist services are often limited or inconsistently available (Atilola, 2017; Bakare et al., 2014). ESSENCE can thus be said to offer a conceptual and practical framework for initiating care in settings where standard diagnostic pathways may not be feasible. As noted by Atilola (2017) and Tekola et al. (2023), substantial gaps persist in the provision and integration of developmental and mental-health services within communities, underscoring the contextual challenges that frameworks such as ESSENCE must address in practice.

Within such environments, a transdiagnostic approach is particularly valuable because it allows for pragmatic screening by non-specialists, guiding early referral even when diagnostic boundaries are unclear (Bitta et al., 2021; Marlow et al., 2019). This feature of ESSENCE directly informed the rationale for the present thesis: to explore whether the framework—and its brief screening questionnaire, the ESSENCE-Q—could feasibly bridge the divide between early identification and limited specialist capacity in rural South Africa. The framework therefore not only underpins the scientific justification for feasibility testing but also provides the conceptual continuity linking all four aims of this research programme.

1.5 THE CLINICAL AND ETHICAL VALUE OF CONTINUITY IN DEVELOPMENTAL CARE

A key value of a transdiagnostic screening framework is its potential to support continuity of developmental care, linking early identification to realistic follow-up support rather than treating screening as a discrete event. In structurally disadvantaged settings—where specialist services are scarce and families face substantial transport, cost, and opportunity barriers—continuity is particularly important because the benefits of early identification depend on whether children and caregivers can access guidance, referral, and sustained support over time. Screening initiatives that do not provide clear follow-through pathways may offer limited clinical benefit and can raise ethical concerns, including the risk of increasing caregiver anxiety without providing meaningful options for action (Bitta et al., 2021; Kakooza-Mwesige et al., 2014).

This argument aligns with global recommendations that developmental surveillance in LMICs should be embedded within a continuum of care—linking identification, referral, intervention, and monitoring—rather than implemented as isolated testing events (Marlow et al., 2019; Richter et al., 2017). A continuity approach is also consistent with the broader "nurturing care" agenda, which frames early detection as one component of integrated systems that combine health, responsive caregiving support, early learning opportunities, and social protection to help children survive as well as thrive (World Health Organization, 2018; World Health Organization, UNICEF, & World Bank Group, 2018).

Continuity is not only a pragmatic service principle but a rights- and equity-relevant obligation in developmental care. The United Nations Convention on the Rights of the Child establishes children's entitlement to the highest

attainable standard of health and to support that enables participation and development (Office of the High Commissioner for Human Rights, 1989). Recent global analyses emphasise that rights-based pathways for children with developmental disabilities require not only identification but ongoing inclusion, participation, and access to supports that families can realistically reach (Olusanya et al., 2025). In contexts of deep inequality, a further ethical concern is distribution of benefit: if follow-up services are limited, screening may disproportionately advantage families with greater resources to travel, advocate, or access private care, unless screening is paired with feasible, stepped options at community and primary-care level (Smythe et al., 2021).

A continuity lens also strengthens implementation design. Evidence from LMIC early-intervention research indicates that identification is most likely to improve outcomes when it is linked to actionable supports—such as parent guidance, non-specialist interventions, and community-based services—rather than functioning as information provision alone (Smythe et al., 2021). In addition, continuity-oriented models in high-adversity settings benefit from trauma-informed approaches, given the high prevalence of trauma exposure and its implications for engagement, trust, and caregiver wellbeing; South African research increasingly emphasises the need for equitable, trauma-sensitive service responses at community level (Chambers et al., 2017; Seedat et al., 2022; Sorsdahl et al., 2020).

The notion of continuity informed design of the present programme of work, in which community-based identification was linked to structured referral and further support. Evaluating the feasibility of this model in a real-world rural context contributes to the evidence base on how transdiagnostic screening approaches can be enacted ethically within constrained systems, and whether

they can achieve both scientific validity and social legitimacy when delivered by trusted, locally trained personnel (Du Toit et al., 2021).

1.6 THE RELEVANCE OF ESSENCE IN STRUCTURALLY DISADVANTAGED SETTINGS

As outlined above, the ESSENCE framework and its accompanying screening instrument, the ESSENCE-Q, therefore offer a practical and ethically grounded approach to improving early identification of NDDs. This is particularly relevant in regions characterised by high levels of poverty, exposure to adversity, limited early-childhood services, and reduced awareness of NDDs, where the challenges described by Bitta et al. (2021) and Marlow et al. (2019) remain pervasive. The framework's emphasis on transdiagnostic screening, early support, and continuity of care is especially pertinent in these contexts, where conventional diagnostic and intervention models are often unworkable (Atilola, 2017; Bakare et al., 2014).

In this programme of work, the process of assessing how feasible and clinically valid the ESSENCE-Q would be in a South-African rural sample was initiated. This responds directly to the gap identified in earlier African research, regarding the scarcity of simple, contextually appropriate screening tools suitable for use by non-specialist personnel (Abubakar et al., 2016; Bitta et al., 2021; Kakooza-Mwesige et al., 2014). Evidence from related feasibility studies in Kenya, Uganda, and South Africa demonstrates that brief, low-burden instruments administered by trained community workers can achieve acceptable psychometric performance while improving access for children otherwise excluded from specialist care (Bitta et al., 2021; Du Toit et al., 2021; Mazibuko & Chimbari, 2020). Building on this body of work, the current research explored whether the ESSENCE-Q could perform a similar bridging function in a rural Western-Cape community.

The clinical-validation phase of this thesis (Aim 3) further examined the diagnostic utility of the ESSENCE-Q when compared with comprehensive developmental and neurological assessments. Establishing the tool's sensitivity and specificity in a real-world African setting contributes to the wider literature on cross-cultural validation of neurodevelopmental screeners (Bitta et al., 2021; Marlow et al., 2019) and informs future implementation frameworks within primary-care services.

Finally, Paper IV (Aim 4) addresses these considerations within a biopsychosocial model of childhood risk. Studies across LMICs show that socioeconomic deprivation, maternal mental-health difficulties, and early adversity interact to increase the likelihood of developmental delays (Brittain et al., 2022b; Honda et al., 2023; Stein et al., 2015). By describing the developmental profiles and family contexts of children identified through ESSENCE-Q screening, this research adds empirical depth to understanding how these mechanisms manifest in rural South Africa.

1.7 THE SOUTH AFRICAN CONTEXT: LOW-INCOME RURAL COMMUNITIES

South Africa continues to rank among the unequal societies in the world, with a Gini coefficient persistently above 60 for more than two decades (World Bank Group, 2025). Within this context, many people in rural communities experience profound and sustained structural disadvantage, characterised by poverty, unemployment, food insecurity, and inadequate access to education, sanitation, and healthcare. For children growing up in these environments, the accumulation of such risk factors contributes to high levels of adverse childhood experiences (ACEs), including exposure to community and domestic violence, household instability, and caregiver mental-health challenges. These intersecting forms of adversity are known to negatively

influence early neurodevelopment and long-term health outcomes (Brittain et al., 2022a; Stein et al., 2015; Tann et al., 2021). More broadly, contemporary syntheses emphasise that early childhood inequities operate through both risk and protective factors—material resources, caregiver wellbeing, early learning opportunity, and community safety—leading to patterned differences in developmental readiness long before formal schooling begins (Walker et al., 2023).

National indicators reinforce the scale of this vulnerability in South Africa. Results from the South African Thrive by Five Index 2021 Survey show a marked socioeconomic gradient in early learning progress by 50–59 months, with substantially fewer children "on track" in lower-income households than in higher-income households (Tredoux et al., 2024). These disparities provide an important backdrop for interpreting developmental screening outcomes in low-income rural settings, where constrained access to early learning opportunities and cumulative household stress may reduce developmental gains prior to school entry. They also support the case for approaches that connect developmental identification with practical supports to strengthen caregiving and early learning environments, rather than treating screening as a stand-alone clinical exercise.

Rural child-health services are primarily delivered through nurse-led primary-healthcare clinics, where developmental surveillance is often limited and focused mainly on physical growth, nutrition, and immunisation. While South Africa's national policies increasingly foreground early childhood development and nurturing care, implementation of comprehensive developmental or neurodevelopmental screening remains inconsistent across routine services. The South African Nurturing Care Framework for Early Childhood Development provides a national policy platform that supports

integrated early childhood approaches from conception to age five, but realising these aims in rural settings remains constrained by resource limitations and uneven service integration (Department of Health, Department of Social Development, & UNICEF South Africa, 2019). Referral pathways to paediatric, psychiatric, or multidisciplinary services are scarce, and where they exist, they are typically concentrated in urban tertiary centres that are geographically and financially inaccessible to most rural families (Atilola, 2017).

This pattern reflects wider inequities observed across sub-Saharan Africa, where distance to services, limited transport, and the opportunity costs of accessing care are major barriers to timely developmental assessment (Bitta et al., 2021; Kakooza-Mwesige et al., 2014). In such settings, families may seek help across fragmented networks of governmental, non-governmental, and community services, but these systems rarely offer structured, continuous developmental surveillance or coordinated follow-up (Atilola, 2017; Tekola et al., 2023). Limited integration between health, education, and social-service sectors further compounds the challenge of delivering early intervention at scale (Marlow et al., 2019).

As a result, many children presenting with subtle or emerging developmental concerns are not identified early, and opportunities for intervention are often delayed or missed altogether. Only a small number of children—often those with visible or severe disabilities—reach specialist assessment, while the majority with milder or less apparent NDDs remain unsupported. The absence of structured screening and integrated care pathways perpetuates the under-recognition of developmental risk and widens existing inequities in child-health and developmental outcomes (Bitta et al., 2021; Kakooza-Mwesige et al., 2014).

Therefore, there is a compelling requirement for feasible, culturally congruent, contextually sensitive screening tools that can be implemented at community and primary-care levels to detect neurodevelopmental concerns early in life. Such approaches should complement existing public-health structures and be deliverable with appropriate supervision and referral linkages (Marlow et al., 2019; Richter et al., 2017). Assessing the feasibility, validity, and clinical applicability of scalable screening approaches in rural South Africa can therefore address an urgent national need while contributing to the global discourse on equitable child-neurodevelopmental care in structurally disadvantaged settings.

2 AIMS

The central objective of this thesis is to examine the extent to which the ESSENCE framework and the ESSENCE-Q neurodevelopmental screening questionnaire for young children can contribute to addressing the substantial gaps in developmental support services within structurally disadvantaged rural communities in South Africa, enabling earlier engagement and, ultimately, fostering improved outcomes for children and their families.

Specific aims are:

1. To delineate the scope of existing research on screening for NDDs in young children in sSA; and specifically, which NDDs are screened for, and by whom, using which screening instruments? (Study I)
2. To evaluate the feasibility of implementing a two-stage screening model employing the ESSENCE-Q neurodevelopmental screening tool—translated into Afrikaans and isiXhosa and administered verbally by trained lay screeners—in a rural, under-resourced community in the Western Cape Province of South Africa, with the aim of identifying a broad spectrum of early childhood neurodevelopmental concerns (Study II).
3. To assess the clinical validity of the translated ESSENCE-Q amongst children aged 3-5 years in a rural South African community by comparing screening outcomes against comprehensive medical, developmental and clinical assessments; and measuring the sensitivity, specificity and positive and negative predictive values of the ESSENCE-Q in this population (Study III).
4. Lastly, to describe the NDD diagnoses and concerns identified amongst the same group of children; and to describe and compare

family sociodemographic factors between children with and without neurodevelopmental diagnoses or concerns (Study IV).

3 METHODS

3.1 STUDY I

The scoping review was undertaken in accordance with the PRISMA-ScR guidelines for scoping reviews (Tricco, 2018) (Appendix A). Four English language databases—PubMed, Web of Science, SCOPUS, and PsycInfo—were systematically searched using a librarian-assisted strategy incorporating keywords related to NDDs and all sub-Saharan African (sSA) countries (Appendix B).

Inclusion criteria targeted studies from January 2012 to December 2023, published in English, involving children aged >2 to <9 years in preschool or early school settings in sSA, screening for NDDs as defined by the ESSENCE framework (e.g., ADHD, ASD, Intellectual Disability, developmental delays, neurological disorders).

Exclusion criteria omitted studies using diagnostic tools only (no screening), those focused solely on visual/auditory impairments, grey literature, and reviews (though reviews were checked for relevant references).

The search was performed twice (March 2023 and March 2024). Retrieved citations were managed in the 'Mendeley' (Mendeley, 2013) and 'Rayyan' (Ouzzani et al., 2016) web-based applications to eliminate duplicates. Titles and abstracts were independently screened in triplicate; full texts were reviewed in duplicate with disagreements resolved via consensus including a third reviewer.

Data extraction was carried out independently by two reviewers employing a structured framework covering participants, concepts, context, methods, and key findings. Quality was appraised using the Newcastle-Ottawa Scale (Wells et al., 2014) adapted for study designs (Appendix C), by two independent raters and a third to resolve differences.

3.2 STUDY II, III AND IV

Description of the setting and population, preparation and community consultation phase, ethical approval and informed consent, as well as data capturing procedures, apply across studies II, III and IV and are thus described here together before each study is further described separately.

3.2.1 SETTING AND POPULATION

The research was undertaken among a community sample drawn from a birth cohort of children born between 01 January 2018 and 31 December 2019 and residing in the small rural town of De Doorns, situated in the Breede Valley in the Western Cape Province of South Africa. Recent national census figures place the Breede Valley population at approximately 212 682 (Statistics SA, 2022), of which De Doorns accounts for about 11 280 residents (5.3% of the subdistrict). Routinely collected provincial hospital data showed that the Breede Valley recorded 7 421 births between 01 January 2018 and 31 December 2019; by extrapolation, roughly 394 of these births are therefore estimated to have occurred in De Doorns. Afrikaans is the dominant home language (64%), followed by isiXhosa (25%) (Statistics South Africa, 2011).

Economic activity in De Doorns is centred around several large export-oriented farming cooperatives that provide the main source of employment. While some farm workers live in formal housing on farms, large numbers -

including seasonal labourers - live in densely populated informal settlements situated along the national highway that traverses the valley. In these settlements, dwellings are predominantly self-constructed from corrugated iron, wood, and plastic. Educational levels are generally low and unemployment high; employment is often temporary or seasonal. Many young children attend privately owned Early Childhood Development (ECD) centres on farms where their caregivers work, or unregistered ECDs within the community itself.

Child development in De Doorns is shaped by both formal and informal capabilities within the community. In the absence of adequately resourced formal services, families often rely on mutual support networks and community adaptation to meet childcare needs. Although no area-specific data exist for the developmental or mental-health burden in the Breede Valley, the socioeconomic realities of De Doorns mirror the national pattern of widespread ACEs. Households are frequently affected by poverty, unemployment, and overcrowding, with concurrent exposure to interpersonal and gender-based violence, household dysfunction, and community-level adversity. These structural disadvantages, long recognised as determinants of developmental and psychosocial outcomes, contribute to an elevated risk of developmental delay and long-term psychosocial difficulty for many children (Brittain et al., 2022a; Grantham-McGregor et al., 2007; Hughes et al., 2017; Lu et al., 2016; Walker et al., 2023). Healthcare and early-developmental services are delivered primarily through the local state primary-healthcare (PHC) clinic, where routine growth, nutrition, and immunisation monitoring are undertaken.

Although developmental surveillance is included in policy frameworks such as the ‘First 1000 Days’ initiative of the National Department of Health, implementation at clinic level remains largely focused on physical health.

Developmental screening, where it occurs, is typically performed by nursing professionals and is seldom accompanied by structured follow-up for developmental or behavioural concerns. Referral for suspected NDDs usually requires attendance at the nearest provincial hospital in Worcester - an expensive and time-consuming journey that most families can ill afford – both in financial and occupational terms. Even when such referrals are made, appointment delays and limited specialist availability mean that many children are not seen promptly.

Beyond the formal health system, a small number of regional non-profit organisations (NPOs) based outside the town - such as the Association for People with Disabilities - provide intermittent outreach and support, mainly for children with visible physical or intellectual disabilities. Informal care and support are also organised through local church groups, childcare centres, and volunteer initiatives, which collectively form fragile but vital social safety nets. However, these networks are loosely coordinated and operate with limited resources, leaving substantial service gaps.

For most caregivers, the primary points of assistance are the nurses at the local PHC clinic and informal community networks. While these relationships play a crucial role in sustaining early childcare, they cannot substitute for structured developmental services. As a result, children with subtly presenting neurodevelopmental problems are often missed. Awareness of developmental risk within the community and among ECD staff is limited, and there are no standardised protocols for referral or intervention. This gap underpinned the rationale for implementing and evaluating an accessible, community-based screening process within the present research.

3.2.2 PREPARATION AND CONSULTATION

As described in Truter et al. (2025b), community-based consultation throughout De Doorns commenced in late 2018, with public health care and ECD staff, parents of children with identified NDDs, regional public healthcare management staff and NPO staff from the region. Translation of the ESSENCE-Q screener, as well as additional supplementary questionnaires, were undertaken in 2019 and early 2020 on the basis of the clinical experiences of this researcher and colleagues in the region. Forward and backward translations were conducted by the relevant Language Departments at Stellenbosch University, with additional input from mothers/caregivers (hereafter referred to as 'mothers') and community workers regarding local colloquial acceptability – through formal focus groups as well as informal discussion. In 2019, four research assistants (RAs) from the region were trained in the general neurodevelopment of children, the ethics and skills required for screening, and in responding to challenges or problems that may arise. These RAs or screen administrators in turn provided ongoing input, feedback and training to the researchers as to the logistical and socio-cultural challenges that may be encountered during community engagement and data gathering phases. This two-way interaction was a critical process of engagement, assisting the research team in understanding complexities in the community that would otherwise have been inaccessible.

3.2.3 ETHICAL APPROVAL

Ethical approval was granted by the Health Research Ethics Committee (HREC) of Stellenbosch University (S20/10/290 PhD), with additional consent from the provincial Department of Health (WC_202103_004) for access to Public Health Centres. The study complied with the Helsinki Declaration and Health Professions Council of South Africa guidelines.

3.2.4 ETHICAL CONSIDERATIONS

In research programmes focused on early identification of NDDs, ethical responsibility extends beyond procedural compliance with institutional and international research guidelines. Screening in contexts of structural disadvantage raises specific obligations related to beneficence, reciprocity, and continuity of care. As Rah et al. (2023) note, developmental screening can only be ethically justified when embedded within a broader framework that links identification to meaningful support. Detecting potential developmental concerns without providing access to appropriate referral, parent guidance, or community resources risks creating distress, stigma, or false expectations.

From an ethical point of view, follow-up care and support for families participating in the research was prioritised. For those who participated in further assessment, comprehensive individualised feedback was provided by a clinical psychologist and occupational therapist. Additional follow-up support included psychoeducation, parental guidance, and referrals to government or non-governmental health and social services as needed, extending community benefit beyond study participants.

Ethical planning also accounted for the socioeconomic vulnerabilities of participants. Many mothers relied on casual or seasonal employment and therefore risked loss of income or work opportunities by attending screening or assessment sessions. In recognition of this, food and refreshments were provided at all times, and efforts were made to schedule participation flexibly and minimise disruption to daily responsibilities. Continuous communication was prioritised throughout the study period. Research staff remained available to answer questions and clarify procedures at every stage, recognising that

sustained engagement was essential to ensuring both informed participation and trust.

Given varying levels of literacy and access to education, a visual consent booklet was developed in consultation with community representatives to support comprehension and transparency during the consent process. This ensured that discussions around consent were accompanied by clear visual aids, helping participants to engage meaningfully with study information and supporting informed decision-making regarding their participation. It was also common for caregivers to raise concerns about other family members, and this was treated as a significant ethical consideration. The research team planned for and responded to these situations by offering appropriate guidance, emotional support, and referrals, ensuring that participation generated benefit rather than unmet anxiety or expectation (Truter et al., 2025b).

These principles informed every stage of the present work. Screening was conducted as part of a broader continuum of care that included detailed feedback to caregivers, linkage to regional and non-governmental support services, and ongoing psychoeducation and parent-training activities. Local RAs were trained not only in screening procedures but also in trauma-informed engagement, ensuring that participation was supportive rather than extractive. In keeping with WHO guidance on ethics in implementation research and early-childhood health systems strengthening, the project sought to create immediate community benefit by developing local capacity for sustainable, community-based developmental surveillance (Richter et al., 2017; World Health Organization, 2020).

Ethically, this approach recognises that screening initiatives generate responsibilities: to ensure that identification is followed by accessible

pathways for assessment and intervention; to empower parents through information and skills; and to strengthen existing community networks rather than substitute for them. Within such a framework, the ethical value of screening is defined not only by scientific validity but also by its contribution to equity, dignity, and the realisation of children's right to developmental support in resource-limited settings.

3.2.5 INFORMED CONSENT AND VISUAL CONSENT BOOKLET

Written informed consent was obtained from mothers before screening and again before detailed assessments. A purpose-designed Visual Consent Booklet was used to facilitate understanding by presenting and explaining the study procedures both verbally and visually (Appendix E). This was done to ensure that consent was genuinely informed and understood, including for mothers with limited literacy and/or formal education.

The booklet was approved by the Stellenbosch University HREC for stand-alone use and conveyed, in illustrated form, all elements of the HREC-approved full-text informed consent document. Specifically, it oriented mothers to the purpose of the booklet and provided an accessible overview of the study, explained why they and their child were being invited to participate, and described how participation and study procedures would unfold should they agree.

It also outlined confidentiality and data-protection measures (including who would have access to study information), summarised potential benefits and risks (including the possibility of harm), and emphasised the voluntary nature of participation by clarifying what would happen if they chose not to take part.

Space for notes and relevant contact details were included for further questions or follow-up (Truter et al., 2025b).

Mothers who provided informed consent were initially asked to complete only the short 12-item ESSENCE-Q screening questionnaire, though procedures for possible participation in phase 2 were also explained. Basic contact information was requested, along with mothers' agreement to be contacted for possible participation in the second phase of the study, at a later stage. Informed consent for those who took part in this second phase, involving detailed data collection, was again verified verbally in person at the time of follow-up, referencing the informed consent booklet used at enrolment.

The guardian of any mother younger than 18 years, was asked to sign an informed consent form, and the young mother herself an informed assent form. Mothers had to understand, at first language level, either English, isiXhosa or Afrikaans – the three languages in which the study information forms and screens were offered. Participants were free to withdraw at any time without any penalty. A small gift (to the value of R50, approximately USD2.50) was provided at screening as a token of thanks. Mothers of children undergoing detailed assessments received a R300 (approximately USD15) grocery voucher in recognition of their time, and each child received an inflatable ball (Truter et al., 2025b).

3.2.6 RECRUITMENT PROCEDURE

Recruitment strategies were adapted in response to local contextual challenges and the disruptions caused by the COVID-19 pandemic. Recruitment and data collection was delayed by the Covid19 pandemic. An initial delay in obtaining provincial Department of Health permission for access to the local primary healthcare (PHC) clinic meant that the Principal Investigator and RAs began

recruitment by visiting as many of the ECD centres in the area as possible, starting with those based on farms. Time was taken to obtain permission and support from farm owners. Through repeated visits and regular formal and informal information sessions, both in the community and on farms, information about the study and its intentions was shared. During these sessions, it was emphasised that the aim was to understand more about, and learn from, the development of all children in De Doorns who were born between 1 January 2018 and 31 December 2019. Locally facilitated awareness of the study was encouraged wherever possible.

Mothers were able to indicate their interest in the study immediately after information sessions or to contact the RAs later using the provided contact details, through the ECD leader, or via other community members. RAs maintained a visible presence in the community throughout this period, for example by visiting ECD centres, stationing themselves outside the PHC clinic on child wellness days, moving through the community on foot while informally sharing information about the study. They also wore clothing that clearly identified them as members of the research team (Truter et al., 2025b).

Procedures around informed consent, enrolment, and ESSENCE-Q screening processes were routinely carried out in locations chosen by mothers as most comfortable for them—including their homes; indoors or outdoors on farms; at ECD sites; at the local public health clinic; or at one of the local churches. A flexible approach to scheduling was maintained, with appointments readily adjusted when families were unable to attend. This flexibility was essential given families' limited resources and transport constraints. Transport options were typically limited to costly, inconvenient, and sometimes unsafe private minibus taxis. For those in employment, taking time off work risked both income loss and job insecurity (Truter et al.,2025b).

Eligibility for the study required children to have been born during the defined period at one of two regional public hospitals, where detailed maternal and birth data were available. Mothers who wished to participate but whose children did not meet this criterion were not turned away. They could still participate in screening and access follow-up support, although their data were not included in the main study dataset.

Recruitment and screening processes commenced in March 2022. Recruitment expectations had been based on extrapolated international prevalence estimates of NDDs, with an anticipated need to screen approximately 400 children to obtain 50 ESSENCE-Q 'positive' cases. This estimate corresponded closely to the estimate of approximately 392 births recorded to mothers living in the study area between 1 January 2018 and 31 December 2019.

3.2.7 DATA CAPTURING PROCEDURE

Study data were captured and managed using REDCap (Harris, 2012), hosted at Stellenbosch University. Screening and consent metadata were recorded electronically on password-protected portable devices and entered into the REDCap database using anonymised participant identifiers. Database access was role-restricted and managed by a designated Stellenbosch University staff member. Signed consent forms were the only paper records and were stored separately in locked filing within locked on-site storage.

3.2.8 INSTRUMENTS

3.2.8.1 *ESSENCE Questionnaire*

The ESSENCE-Q (Hatakenaka et al, 2016) is a short, 12-item caregiver-reported screening tool developed in alignment with the ESSENCE framework (Gillberg, 2012). It is designed to identify a wide range of developmental

concerns without requiring prior diagnostic clarity and captures caregiver concerns across multiple domains, including general development, communication and language, social interaction, motor coordination, attention, activity regulation, behaviour, mood, eating, and sleep. Concerns in each domain are rated on a three-point Likert scale ("No" = 0, "Maybe/A little" = 1, "Yes" = 2), generating a total score between 0 and 24.

Validation studies in Sweden (Landgren et al., 2022), Japan (Hatakenaka, 2017), and India (Kattimani et al., 2022) have demonstrated the tool's utility in identifying children that require further developmental assessment. Importantly, the ESSENCE-Q has not yet been tested in African contexts. However, its brevity, simplicity, and broad scope suggest that it may be particularly well suited to under-resourced, multilingual environments such as rural South Africa. In such contexts, where developmental concerns are often under-recognised and where services are limited, the ESSENCE-Q offers a promising avenue for initiating developmental care pathways.

Research available into the feasibility of ESSENCE-Q as a screening tool for children has thus far generally focused on clinical contexts, where families present with concerns regarding a child's neurodevelopmental signs and symptoms. The majority of this research has been in locations where functional state- and/or privately funded health services are in place, precluding the necessity to address social and/or public health service conditions that might impact the feasibility of using the ESSENCE-Q. This may not be the case in many LMICs.

Various existing cut-off criteria was considered for the purpose of this study. The authors of the ESSENCE-Q originally suggested 1≤ "Yes" or 2≤ "Maybe/a little", while Hatakenaka (2017) in a Japanese study found the optimal cut-off

to be 1≤ “Yes” or 3≤ “Maybe/a little”. In India, scores ≥4 yielded the most optimal balance between validity and sensitivity (Kattimani, 2022). Since the latter was the only other study on the ESSENCE-Q conducted in a LMIC, the same cut-off was initially selected for the present study.

3.2.8.2 *Autism – Tics, ADHD and other Comorbidities (A-TAC) Inventory*

This is a structured parent-report screening tool developed to identify a broad range of neurodevelopmental symptoms, with a strong focus on ASD and ADHD (Hansson et al., 2015). It contains 96 items across 20 modules. Responses are scored 0 (“No”), 0.5 (“Yes, to some extent”), or 1 (“Yes”). Only age-appropriate modules were used in this study. The ASD subscale has excellent diagnostic validity (AUC=0.98) with cut-off scores of ≥4.5 indicating ‘elevated risk’ and ≥8.5 indicating ‘clear risk’ (Mårland et al., 2017). The ADHD subscale (AUD = 0.93) uses cut-offs of ≥6 for ‘elevated risk’ and ≥12.5 for ‘clear risk’ (Mårland et al., 2017). Whilst some work was done to adapt the A-TAC for this study (Nel & Kafaar, 2022), it has not yet been validated in South Africa – but it does show good sensitivity and specificity across several other populations.

3.2.8.3 *Strengths and Difficulties Questionnaire (SDQ)*

The SDQ (Goodman, 1997) is an extensively utilised 25-item behavioural screening questionnaire that assesses emotional and behavioural difficulties in children. It includes five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity/Inattention, Peer Relationship Problems, and Prosocial Behaviour. A Total Difficulties Score is calculated from the first four subscales. The SDQ has been used internationally across diverse contexts. While UK normative data is typically used (Goodman, 1997), no South African norms exist and it has not yet been fully validated in African preschool populations (Hoosen et al., 2018). Therefore, UK cut-off scores for children

aged 2–4 were applied provisionally. The Total Difficulties Score is categorised as 'Close to average' (0–12), 'Slightly raised' (13–15), 'High' (16–18), or 'Very high' (19–40). Prosocial scores are similarly categorised from 'Close to average' to 'Very low' (YouthInMind, 2015).

3.2.8.4 *WHO 20-item Self-Reporting Questionnaire (SRQ)*

This tool screens for common mental disorders, particularly depression and anxiety, in primary healthcare settings (Beusenberg & Orley, 1994). It comprises 20 yes/no items and is scored 0 or 1 per item, for a total score of up to 20. A cut-off score of ≥7 was utilised to denote probable mental health concern among women, based on South African studies (van der Westhuizen, 2016).

3.2.8.5 *WHO Alcohol Use Disorders Identification Test (AUDIT)*

This 10-item questionnaire identifies risky or harmful alcohol use. Scores of ≥8 suggest hazardous drinking, ≥15 suggest likely alcohol dependence, and ≥20 indicate severe alcohol-related problems (Babor et al., 2001).

3.2.8.6 *WHO Drug Use Disorders Identification Test (DUDIT)*

A corresponding 11-item screening tool for drug use. The general population cut-off score for women is 2 or more, indicating potentially problematic drug use (Berman et al., 2002). Neither AUDIT nor DUDIT have been validated in this specific population, but are internationally recognised for use in primary health and research settings.

The use of these WHO screening instruments reflects alignment with broader national and global early childhood development policy frameworks. Together, the SRQ, AUDIT, and DUDIT form part of an integrated package of mental-health and psychosocial screening tools recommended by the World Health Organization for use in primary healthcare and maternal–child settings.

In South Africa, their use aligns closely with the South African Nurturing Care Framework (Department of Health, Department of Social Development, & UNICEF, 2019), which emphasises the interdependence of caregiver wellbeing and early childhood development. The framework identifies maternal mental health, substance use, and responsive caregiving as critical components of nurturing care, recognising that early childhood outcomes are inseparable from the health and stability of caregivers. Routine use of these WHO instruments within public healthcare settings therefore operationalises the Nurturing Care Framework's goals of integrated, family-centred, and preventive intervention across the life course (World Health Organization, 2018; Department of Health et al., 2019).

3.2.8.7 *Developmental Assessment: Griffiths Scales of Child Development – 3rd Edition (Griffiths-III)*

The Griffiths-III (Stroud et al., 2016) assesses children aged 0–6 years across five domains: Foundations of Learning, Language and Communication, Eye and Hand Coordination, Personal–Social–Emotional Development, and Gross Motor Skills. It provides domain-specific scores and an overall General Development Score. Although the Griffiths-III was not standardised in South Africa, local clinicians and researchers contributed to adapting the tool for better cultural neutrality (Cronje et al., 2022). Each assessment takes approximately two hours, including settling time and breaks.

3.2.9 ADDITIONAL PROCEDURES: STUDY II

To assess feasibility, this study projected that approximately 394 mother-child pairs could be screened over one year, utilising 2-3 RAs that actively recruited four days per week. This was based on the estimated number of live births in

De Doorns during the defined period, and targeting screening of all/most children born during this period. Based on international prevalence rates (~10%), and with consideration of possible higher local rates due to adverse exposures, it was anticipated that at least 50 positive ESSENCE-Q screens would be obtained from this group.

Feasibility was assessed through mixed methods along four dimensions:

a) Screening administrators' experiences via a semi-structured focus group interview, which was recorded and analysed using the Braun and Clarke reflexive thematic analysis (2006), to evaluate their endorsement of the instrument, process, and handling of participant issues;
b) Mothers' feedback via a brief verbally administered questionnaire with a 5-point Likert scale, where ≥80% positive responses indicated support for feasibility;
c) Research team field observations and reflections to identify and resolve challenges without altering the project's core focus;
d) Documentation of training time, resources, and costs for screening administrators to guide future replication.

For RA feedback, an independent team member conducted a focus group with three trained RAs, using a semi-structured format with open-ended questions. This interview was recorded, transcribed and analysed qualitatively. Two independent researchers generated initial codes, which were reviewed and refined by the PI. Semantic as well as latent coding were used. From these, themes were generated, assembled and reviewed collaboratively through a predominantly inductive process, within a constructionist epistemology and an experiential orientation.

Mothers' feedback questionnaires comprised 7 statements rated on a 5-point Likert scale with visual supports (Appendix F), administered to 91 of 100 available mothers during follow-up sessions, with the Afrikaans translation used exclusively. Responses were collected in small groups with verbal psychologist guidance to ensure understanding and confidentiality. Responses were scored by adding all values to obtain a sum score (possible range 7-35).

Ongoing qualitative feedback from RAs and the research coordinator, along with critical reflection, supplemented the focus group data. Training sessions were documented to quantify the time and resources needed for screening administrator preparation.

3.2.10 ADDITIONAL PROCEDURES: STUDY III

Following recruitment, informed consent and screening (as described in 3.2.3 and 3.2.4), a subset of 100 children were invited for more comprehensive clinical assessments during a second visit. Half of these children had screened positive on the ESSENCE-Q (scores ≥4) and half, negative. This second (assessment) phase took place at Stellenbosch University's Worcester Rural Campus, approximately 33km from De Doorns, and commenced in October 2022. Transport was arranged and provided to mothers and children by the study team.

All assessors were blinded to ESSENCE-Q screening results. The assessment protocol included:

a) verbal administration of demographic, medical, and neurodevelopmental questionnaires to mothers in Afrikaans or isiXhosa;

b) a physical examination of the child by senior research nurses; including anthropometric measurements (weight, height, head circumference), general medical observations, and screening for any visible developmental abnormalities.

(c) administration of the Griffiths-III by an experienced psychologist;

(d) a comprehensive clinical evaluation by a paediatric neurologist who reviewed all assessment data (excluding the ESSENCE-Q) and conducted in-person examinations when indicated.

Diagnostic consensus was reached between the paediatric neurologist and psychologist, based on comprehensive clinical presentation. Holistic clinical judgement was applied, particularly in cases with borderline Griffiths-III scores. With cognisance of issues around cultural differences and the fact that the Griffiths-III is not formally standardised in South Africa, some children with subscale scores <70 were not formally diagnosed with Global Developmental Delay (GDD) if not supported by clinical evidence. For this study, intellectual developmental disorder was encompassed under GDD and not reported separately. Final diagnostic categorisation consisted of three groups: (i) formal DSM-5 NDD diagnosis; (ii) clinical concern without formal diagnosis (including children with significantly low scores on Griffiths-III subscales); and (iii) no clinical concern. In the statistical analysis to assess the ESSENCE-Q validity, Groups (i) and (ii) were combined as '*children presenting with clinical concern*' for comparison with screening outcomes. A summary of the study process is presented in Figure 1.

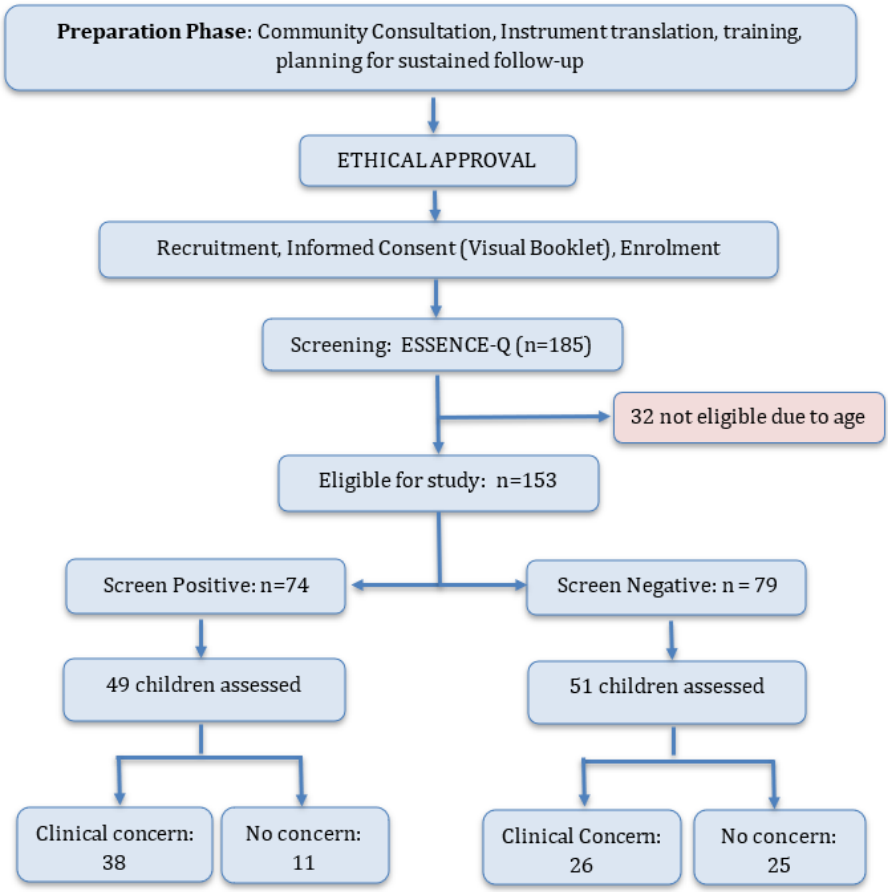

Figure 1: Flowchart of study process for Study III

Statistical Analysis

Power calculations determined that 41 screen-positive children were necessary to achieve statistical power above 0.80 for validity analyses with alpha set at 0.05. Thus, approximately 50 positives and 50 negatives were targeted for assessment. Statistical analyses were conducted using STATA SE18.5 (StatCorp, 2023). Descriptive statistics summarized demographic and clinical data for all screened children. Comparisons between screening-positive and

negative groups were conducted using independent samples t-tests for continuous variables and Chi-squared or Fisher's Exact tests for categorical variables, depending on distribution and assumptions. Internal consistency of the ESSENCE-Q was evaluated via Cronbach's alpha, expecting moderate inter-item correlations reflecting distinct but related constructs. Diagnostic validity metrics (sensitivity, specificity, positive and negative predictive values) were calculated with 95% confidence intervals using STATA's diagtest command, initially applying the ≥4 cut-off and then testing alternative thresholds including ≥3, ≥2, and previously published criteria (Hatakenaka et al., 2016).

3.2.11 ADDITIONAL PROCEDURES: STUDY IV

Further analysis of assessment outcomes was conducted in Study IV, in particular those presenting with either a formal DSM-5 diagnosis or clinical concern, in order to describe clinical characteristics.

Statistical analysis

Descriptive statistics were calculated for all participants, stratified by assessment outcome group. Differences in demographic and clinical variables between children with any identified concern (diagnosis or clinical concern) and those without, were analysed using t-tests (continuous variables) and chi-square tests (categorical variables), with significance set at $p<0.05$. Anthropometric data were converted into WHO Z-scores for weight-for-height (WHZ) and head circumference-for-age (HCAZ) and manually plotted on WHO growth charts. All data were entered into REDCap (Harris, 2012) using anonymised identifiers, and analysed using STATA SE18.5 (StataCorp, 2023).

4 RESULTS

4.1 STUDY I

A total of 732 articles were identified across four databases: PubMed (214), Web of Science (104), SCOPUS (276), and PsycInfo (138). After removing duplicates, 546 abstracts remained for screening. Twelve articles, representing ten unique studies, met the inclusion criteria and were included in this review. These comprised six studies from South Africa, three from Kenya (all from a single large epidemiological project), two from Uganda, and one from Malawi (Truter et al., 2025a).

While six studies included children who were already nine years of age, they were retained, as all participants fell below WHO's lower limit for adolescence (10 years), and the slight age difference did not compromise the relevance to the research question. An additional nine studies that included children in our specified age range, were excluded due to their inclusion of children under two years without age-stratified data.

The included studies varied considerably in design, population, and screening focus. Two screened explicitly for multiple NDDs (Bitta et al., 2021; Kakooza-Mwesige et al., 2014), while one - nested within a broader study—focused primarily on epilepsy (Kind et al., 2017). Four studies investigated specific NDDs (e.g. ADHD, autism, or motor coordination disorders), and five explored developmental delays across several domains such as motor, communication, and cognitive functioning.

Tools used included the 23-Question Questionnaire (23Q) (Kakooza-Mwesige et al., 2014), the NDST (Bitta et al., 2021), the Kiddie Schedule for Affective Disorders and Schizophrenia - Present and Lifetime Version (K-SADS-PL)

(Kariuki et al., 2020), the Social Communication Questionnaire (SCQ) (Arinda et al., 2021), the Little Developmental Coordination Disorder Questionnaire (Little DCDQ) (Venter et al., 2015) and the PEDS (Du Toit et al., 2021), several of which were translated or adapted for local contexts. Most studies reported good sensitivity for identifying developmental difficulties, although specificity varied widely. In some studies, such as those conducted in Kenya and Uganda, screening tools like the NDST and 23Q were found to be both feasible and psychometrically strong in low-resource settings. Others, such as the mHealth-based PEDS and Little DCDQ, highlighted limitations in specificity. Two studies explored developmental outcomes in children with HIV, finding significantly increased risk of disability compared to non-HIV peers (Devandra et al., 2013; Knox et al., 2018). Two further studies (Brittain et al., 2022b; Shuffrey et al., 2022) used screening instruments to assess the influence of maternal mental health and adverse childhood experiences on child development, reporting associations with lower cognitive or socio-emotional scores, but no follow-up diagnostic confirmation was conducted.

Overall, while the included studies demonstrated substantial heterogeneity in methodology, population, and outcomes, the findings suggest growing regional interest and emerging capacity to identify NDDs among young children in sub-Saharan Africa. A full summary of included studies is provided in Table 1.

Table 1: Summary of studies screening for NDDs in sub-Saharan Africa

Author	Country	Target NDDs	Tool(s) Used	Age Range	Key Findings
Kakooza-Mwesige et al.	Uganda	Multiple NDDs	23Q (adapted TQ)	2–9 yrs	Feasible tool; prevalence: 10–13/100; variable sensitivity (0.55–0.80).
Bitta et al.	Kenya	ADHD, autism, epilepsy	NDST, TQ	6–9 yrs	High sensitivity (87.8%) and specificity (83.3%); NDST preferable.
Kariuki et al.	Kenya	ADHD	K-SADS-PL	6–9 yrs	97% sensitivity, 95% specificity; strong reliability for ADHD diagnosis.
Kind et al.	Kenya	Epilepsy	NDST	6–9 yrs	Epilepsy prevalence: ~21/1000; NDST effective for seizure identification.
Arinda et al.	Uganda	Autism	SCQ	2–9 yrs	45% screened positive; strong link with developmental delays.
Mazibuko & Chimbari	South Africa	Receptive language	IRVT (isiZulu)	4–<7 yrs	Highlighted need for culturally adapted language tools.
Venter et al.	South Africa	Motor coordination	Little DCDQ	3–5 yrs	Good reliability ($\alpha > 0.8$); low sensitivity (57%).

Author	Country	Target NDDs	Tool(s) Used	Age Range	Key Findings
Du Toit et al.	South Africa	Developmental delay	PEDS (mHealth)	3–7 yrs	High sensitivity (92.6%); low specificity (22.5%).
Devendra et al.	Malawi	Disability (HIV context)	TQ	2–9 yrs	HIV+ children 8× more likely to have disabilities.
Knox et al.	South Africa	Disability (HIV context)	TQ (isiZulu)	4–6 yrs	High sensitivity (90–100%); low specificity (51.2%).
Shuffrey et al.	South Africa	Cognitive & socioemotional development	BSID-III ST	3 yrs	Lower scores linked to maternal depression/anxiety.
Brittain et al.	South Africa	Development & socio-emotional outcomes	ASQ-3	3–5 yrs	Maternal ACEs linked to poorer socioemotional outcomes.

Abbreviations: 23Q = 23 Questions; ASQ-3 = Ages and Stages Questionnaires – Third Edition; BSID-III ST = Bayley Scales of Infant and Toddler Development – Third Edition Subtest; IRVT = Ingwavuma Receptive Vocabulary Test; K-SADS-PL = Kiddie Schedule for Affective Disorders and Schizophrenia – Present and Lifetime Version; Little DCDQ = Little Developmental Coordination Disorder Questionnaire; NDD = Neurodevelopmental Disorders; NDST = Neurodevelopmental Screening Tool; PEDS = Parents' Evaluation of Developmental Status; SCQ = Social Communication Questionnaire; TQ = Ten Questions Questionnaire;

Quality evaluations with the Newcastle-Ottawa Scale showed considerable variability, with cross-sectional studies rated from "Very good" to "Unsatisfactory," and cohort and case-control studies receiving ratings between "Good" and "Fair" (Appendix D).

4.2 STUDY II

The findings are presented according to thematic domains derived from the different data sources, reflecting the perspectives of RAs, participating mothers, and field observations of the screening process and context.

Screening Process and Participation

Over 12 months, 185 participants were screened, of whom 153 met eligibility criteria, yielding the intended sample of 50 children who screened positive.

Reflexive Thematic Analysis: Research Assistant (RA) Feedback

Five central themes were generated through a process of reflexive thematic analysis (Braun & Clarke, 2006) of the focus group data: Mode of Engagement, Flexibility of Processes, Concept Accessibility, Trauma and Resource Deprivation, and Participant Experience (Truter et al., 2025b).

RAs emphasised the importance of respectful, in-person interactions that allowed them to build trust and explain complex concepts to mothers, who often had limited formal education and varied knowledge of child development. Flexible, informal outreach strategies—such as walking through communities and setting up tables outside clinics—proved more effective than formal methods.

RAs observed that the ESSENCE-Q screening tool was well received; mothers found the visual materials helpful, and RAs believed other community members could be trained to use the tool with appropriate preparation. High levels of trauma and resource deprivation in the study setting were apparent, with mothers disclosing distressing experiences that highlighted the need for accessible psychosocial support for both participants and RAs.

Participant (Mother) Feedback

Feedback was obtained from 91 of the 100 mothers who participated in detailed assessments and was overwhelmingly positive, with 100% of questionnaire responses being rated 4 or 5 on the five-point scale.

Operational and Logistical Challenges

Field observations identified logistical and communication challenges, especially around telephone-based procedures, which proved impractical due to limited phone access, inconsistent contact information, and low privacy. Additional non-neurodevelopmental concerns—such as domestic violence, substance abuse, and broader health issues—were frequently raised during screening, requiring referrals to support services.

The study also highlighted resource needs, including transport, time-intensive planning, and the requirement for a trained, multidisciplinary team for RA training and supervision. While the ESSENCE-Q screening itself was brief, the associated tasks—consent, scheduling, and addressing participant concerns—demanded significant time and effort.

Feasibility and Psychosocial Context

Despite these challenges, the feasibility of a community-based, relationship-driven screening model was supported, provided that adequate staffing, training, and support systems were in place.

A notable finding across all data sources was the pervasiveness of trauma exposure among participants and research staff. Accounts of interpersonal violence, chronic hardship, and secondary traumatic stress emerged

consistently during data collection, underscoring the extent of psychosocial burden in the study population.

4.3 STUDY III

During the 12-month recruitment period, screening was completed for 185 children. Of these, 153 met the age-related inclusion criteria, with 74 (48%) screening positive and 79 (52%) screening negative on the ESSENCE-Q at the established cut-off score of ≥4. The target number of positive screens was reached much sooner than expected, with 74 positive results after only 153 eligible recruitments (Truter et al,.2025c). The total number screened was therefore substantially lower than projected. Because recruitment proceeded more slowly than anticipated and sufficient positive cases had been identified, screening concluded once detailed assessments were scheduled and confirmed for 50 children who screened positive. Screening was also offered, on request, to an additional 31 mother–child pairs whose children fell outside the study's defined age range and who were subsequently referred to the ESSENCE outreach team.

The majority of participating children were Afrikaans-speaking (93%), and the biological mother was the primary caregiver for 95%. The median age at screening was 3.9 (IQR 3.4 – 4.4) years. Mothers most frequently reported concerns regarding their children's communication, social interaction, and mood. The internal consistency of the ESSENCE-Q was moderate (Cronbach's $\alpha = 0.68$).

Detailed clinical assessments were completed for 100 children, balanced by screen result and gender, with a comparable demographic profile. Clinical concern was identified in 64 of the 100 assessed children, 36 of whom received a DSM-5 diagnosis.

Using scores of 4 as cut-off, as applied in our initial analysis, the ESSENCE-Q demonstrated a sensitivity of 59% (95%CI: 50-69) and a specificity of 69% (95%CI: 60-78), yielding a positive predictive value (PPV) of 78% (95%CI: 69-86) and a negative predictive value (NPV) of 49% (95%CI: 39-59). Applying Gillberg's proposed criteria (≥1 "Yes" or ≥3 "Maybe/A little") improved sensitivity to 75% (95%CI: 67-83) but reduced specificity to 42% (95%CI: 31-51).

4.4 STUDY IV

Study IV describes the clinical characteristics of the 100 children who received detailed clinical assessments. This group consisted of 54 boys and 46 girls, with median age 4.2 years (IQR 4.0–4.9). All children and their mothers were Afrikaans-speaking, and 96 lived with their biological mother. There were three sets of twins, and one set of siblings from the same parents.

Neurodevelopmental concerns were identified in 64 children: 36 met DSM-5 diagnostic criteria and 28 presented with clinical concerns or Griffiths-III subscale scores <70 that warranted further follow-up. The remaining 36 children showed no clinical concerns. The most common diagnosis was GDD (n = 26), followed by ADHD (n = 9), ASD (n = 5), Developmental Language Disorder (DLD) (n = 2), and DCD (n = 2). A quarter of those with diagnoses were assessed as presenting with more than one condition (Table 2).

Table 2: Summary of clinical diagnoses among 100 assessed children

Diagnostic Category	Diagnosis / Clinical Description	Number of Children n=100 (%)
Neurodevelopmental Disorders (DSM-5 Diagnosed)	GDD	22 (22)
	GDD + ADHD	2 (2)
	GDD + ADHD + DCD	1 (1)
	ADHD (only)	4 (4)
	GDD + ASD	1 (4)
	ASD + Hypoxic-Ischaemic Encephalopathy	1 (1)
	ASD + Mild Hemiplegia	1 (1)
	ASD + ADHD	2 (2)
	DLD	1 (1)
	DLD + DCD	1 (1)
Subtotal (children with DSM-5 diagnoses)		**36 (36)**
Clinical Concern without DSM-5 Diagnosis	Clinical concern requiring monitoring / further information	24 (24)
	Low Griffiths-III subscale score (< 70) only	4 (4)
Subtotal (children with clinical concern)		**28 (28)**
No Clinical Concern Identified		**36 (36)**
TOTAL SAMPLE		**100 (100)**

Abbreviations: ADHD=Attention Deficit Hyperactivity Disorder; ASD=Autism Spectrum Disorder; DCD=Developmental Coordination Disorder; DLD=Developmental Language Delay; GDD=Global Developmental Delays; Griffiths-III=Griffiths Scales of Child Development Third Edition.

Possible (but unconfirmed) ADHD was noted in seven additional cases, and four children showed ASD-related features requiring further observation. Other concerns included socio-emotional difficulties, trauma-related problems, and developmental vulnerability linked to social or family stressors.

Griffiths-III results showed significantly lower median Developmental Quotients (DQs) across all subscales—and on the General Development Scale—for children with clinical concerns or diagnoses compared with those without. Subscale A (Foundations of Learning) had the highest proportion of DQ scores <70, affecting 38 children.

On the A-TAC, 14 children had autism-subscale scores ≥4.5 (indicating elevated risk); only two exceeded the threshold for clear ASD risk (≥8.5). Of these, one had a clinical ASD diagnosis and the other a significant trauma history. For ADHD, 32 children scored ≥6 on the subscale, including three with scores ≥12.5.

The SDQ identified 23 children with high Total Difficulties scores and 13 with low Prosocial scores, largely overlapping with those who had clinical concerns or diagnoses.

Physical examination findings indicated undernutrition in 12% of children (WHZ < −2 SD) while 5% had had WHZ > 2SD. No major congenital anomalies or syndromes were detected. Most children (85%) were up to date with immunisations.

Birth and maternal data were available for 81 children: 22% were born preterm (<37 weeks) and the median birth weight was 2970 (IQR: 2600–3280) grams. Thirteen mothers (16%) were living with HIV, and none of their children were HIV-positive. Median maternal age at delivery was 27.6 (IQR: 22.2 - 32.7) years. Caesarean sections accounted for 11% of births, and 6% occurred before arrival at hospital.

Sociodemographic data from 96 mothers showed 31% living in informal dwellings; 76% did not complete secondary education; and 77% were employed (full time / part-time / studying). Nearly half of fathers (41%) had

incomplete secondary education, and only 42% lived with the mother. Financial and emotional support from fathers varied: 77% contributed financially and 63% provided emotional support. Over a third of mothers (34%) screened positive for mental-health distress (SRQ >6), and 15% reported alcohol use at potentially hazardous levels (AUDIT >7). One-third also reported significant life stress during pregnancy. No statistically significant demographic or perinatal differences were found between children with clinical concerns and those without (Truter et al., 2025d).

5 DISCUSSION

South Africa's Thrive by Five Index reports that children in structurally disadvantaged households are far less likely to be 'on track' at 50–59 months (~38% vs ~58% in the most advantaged group), highlighting the system-level gap our study addresses (Tredoux et al., 2024). With this national context in view, the findings will now be considered in greater detail.

5.1 STUDY I – SCOPING AN UNDEREXPLORED FIELD

The scoping review confirmed the limited amount of published research on neurodevelopmental (ND) screening among preschool-aged children in sub-Saharan Africa (Truter et al., 2025a). This scarcity was not unexpected: existing ND research in the region has historically centred on infancy (0–2 years), largely within the contexts of survival, growth, and infectious-disease control. Studies addressing the 2–8 year age group remain rare.

Where screening does occur, it is frequently narrow in scope, targeting single disorders or developmental domains. Only two studies simultaneously screened for multiple NDDs, reflecting initial steps in the emergence of transdiagnostic approaches in sSA. Tools such as the TQ, the NDST, and the PEDS were most commonly used.

The findings emphasise both the conceptual and infrastructural gaps in regional NDD research. Large, high-quality studies such as the Kilifi project in Kenya (Bitta et al., 2021) and the Ugandan community screening programme (Kakooza-Mwesige et al., 2014) demonstrate feasibility but also underline how exceptional such initiatives remain. The review therefore provided clear justification for the current research programme: to extend knowledge on accessible, contextually valid, community-based,

transdiagnostic screening for preschool children in disadvantaged African contexts.

5.2 STUDY II – THE FEASIBILITY OF COMMUNITY-BASED SCREENING

The feasibility study assessed whether the ESSENCE-Q could be administered effectively within a rural, structurally disadvantaged environment. Recruitment and screening in the De Doorns community revealed the practical challenges of conducting developmental research in structurally disadvantaged settings (Truter et al., 2025b). Barriers included transport and scheduling difficulties, inconsistent contact information, inconsistent and limited telephonic availability, low literacy, and competing socioeconomic pressures on caregivers; existent within a setting where carers may be disproportionately affected by structural inequities, reflecting broader issues of social injustice.

Despite these constraints, the ESSENCE-Q proved feasible when implemented through a relationship-driven, community-embedded model. In-person engagement, flexibility in scheduling, and verbal administration were essential for success. Mothers valued being asked about their children's development, and the screening process itself created space for conversation about previously unvoiced concerns—and indeed, awareness-raising.

However, the feasibility of screening also depended on the psychological safety of both participants and field staff. The study setting was marked by pervasive trauma and deprivation, which required continuous emotional support for mothers and debriefing for RAs. These observations mirror other South-African community-based research showing that trauma-informed and context-responsive engagement is essential for ethically sound practice in disadvantaged areas (Chambers et al., 2017; Sorsdahl et al., 2020).

The absence of a comprehensive local clinical infrastructure might superficially appear to render any screening effort irrelevant. Yet, our experience revealed a foundation of local capacity that could be mobilised. Clinic nurses, auxiliary health workers, and ECD teachers already functioned as informal observers of child development and were trusted by caregivers. With targeted training and supervision, they can act as first-line identifiers of children at risk. The inclusion of non-health professionals as RAs demonstrated that local residents can successfully deliver and sustain screening processes when adequately supported.

The design of the ESSENCE-Q also contributed to the feasibility of screening. Its simple yes/maybe/no response format and holistic, transdiagnostic orientation allowed meaningful participation even among caregivers with limited literacy. In a community where specialist diagnostic services are rare, identifying a "child of concern" is more actionable than seeking definitive categorical diagnoses. Thus, feasibility of the screening programme in this community was not only methodological but relational: a function of trust, training, and local collaboration.

5.3 STUDY III – VALIDITY AND PSYCHOMETRIC PERFORMANCE

The third study evaluated the clinical validity of the ESSENCE-Q against detailed multidisciplinary assessments (Truter et al., 2025c).

It was noteworthy that the desired amount of children that screened positive, was already found after 153 children were screened—rather than the anticipated 400. This may reflect heightened motivation to participate among

mothers who had existing concerns about their children's development. It is not believed to reflect actual prevalence in this community, as the study did not allow for such broader conclusions. Nevertheless, these findings suggest that structurally disadvantaged communities characterised by high rates of ACEs may show an elevated prevalence of neurodevelopmental problems relative to less disadvantaged populations (Brittain et al., 2022; Hughes et al., 2017; Lu et al., 2016; Walker et al., 2023).

The fact that all 100 children who underwent assessment were Afrikaans-speaking may indicate a recruitment bias in the assessment phase. Although every effort was made to include isiXhosa-speaking participants—through translation of study materials and the training of isiXhosa-speaking RAs—uptake among this group was lower at the screening stage, and none proceeded to assessment. One contributing factor may have been that the isiXhosa-speaking research assistant obtained new employment during the course of the study.

Informal feedback from RAs also suggested that locating isiXhosa-speaking mothers who had participated in screening was more challenging, possibly because some were seasonal workers who travelled between regions for employment. The sensitivity and PPV of the ESSENCE-Q found in this study using Gillberg's originally proposed criteria, the ESSENCE-Q achieved a sensitivity of 75% and a PPV of 70%, which may be considered moderate for a screening instrument (Power et al., 2013). Although the specificity (42%) and NPV (48%) were low, it may be useful to interpret screening tools such as the ESSENCE-Q primarily from a rule-in perspective—that is, as instruments that help to identify children who may warrant further assessment—rather than from a rule-out perspective that seeks to exclude those without concern. From this standpoint, the reduced specificity and NPV may be considered

acceptable, provided that referral systems are equipped to manage follow-up appropriately.

Nevertheless, care must be taken to avoid overburdening already limited healthcare services with excessive false positives requiring assessment (e.g., Marlow et al., 2019). Overall, the psychometric profile of the ESSENCE-Q in this sample suggests that it can identify many—but not all—children with developmental concerns. However, its performance was somewhat weaker in this population compared with results reported in previous validation studies from Sweden, Japan, and India (Fernell & Gillberg, 2023; Hatakenaka et al., 2016; Kattimani et al., 2022).

When compared with other broad-based screeners, the ESSENCE-Q performed less well on standard psychometric metrics. The NDST used in Kenya demonstrated sensitivity and specificity above 80% (Bitta et al., 2021), while the South-African mHealth PEDS achieved high sensitivity (93%) but lower specificity (23%) (Du Toit et al., 2021). These contrasts show that structured, guided questioning—as in the NDST and PEDS—can improve caregiver comprehension. The ESSENCE-Q, by contrast, depends on reflective parental judgment across multiple domains, which may be influenced by differing levels of awareness or culturally shaped understandings of early child development and neurodevelopmental problems.

A further consideration is the frame of reference available to caregivers when judging whether a developmental difference is a "concern." The ESSENCE-Q explicitly tracks caregiver concern, but "concern" is not a neutral construct: it is shaped by what is visible, discussable, and comparable in the caregiver's everyday context. In De Doorns, mothers may implicitly evaluate their child against peers within the local community—peers whose developmental opportunities and risk exposures are themselves shaped by structural

disadvantage. Where developmental variation is widespread, certain differences may be experienced as typical, or at least not salient enough to be named as a concern, even when a standardised assessment later identifies clinically meaningful difficulty. In this sense, lower sensitivity may partly reflect not only limited developmental knowledge, but also the ways in which adversity can recalibrate normative expectations and reduce the signs of difficulty within everyday comparison groups. This reinforces the importance of interpreting caregiver-report screeners as contextually situated measures—capturing both child functioning and the caregiver's socially-shaped threshold for worry.

These contextual factors are likely to have influenced these results. Indeed, in communities where adversity is widespread, developmental differences can be normalised, lowering sensitivity (Brittain et al., 2022a; Stein et al., 2015). Linguistic and cultural nuances may also have affected interpretation despite rigorous translation and pilot testing.

One practical implication is whether screening performance might be strengthened by incorporating a brief, contextually appropriate language component. Early language ability often functions as a sensitive marker of broader developmental vulnerability, and structured language prompts may be easier for caregivers to judge than more abstract or multi-determined behaviours (e.g., "attention," "social reciprocity"). A locally developed list of familiar words and simple functional language behaviours—administered as guided questions (e.g., whether the child uses specific words, combines words, or follows simple instructions)—could potentially provide an additional "anchor" that supports caregiver interpretation and improves discriminatory accuracy. This study did not test such an addition, and it is therefore proposed only as a future refinement rather than a conclusion. However, this suggestion

aligns with the broader observation that guided, behaviourally specific questioning can improve caregiver comprehension and reduce interpretive variability.

Nevertheless, the ESSENCE-Q's conceptual breadth and simplicity remains relevant and beneficial in resource-constrained settings. It provides a quick, low-cost means of highlighting global developmental concern and initiating referral or support. The findings suggest that it may be used as a first-level screening tool within a two-tiered model, followed by more detailed, locally validated assessment.

5.4 STUDY IV – CLINICAL PROFILES AND CONTEXT

Clinical assessments of the 100 children revealed that 36 of these children met DSM-5 NDD diagnostic criteria, a further 28 children presented with subthreshold but significant difficulties, and the remaining 36 children showed no clinical concern. GDD was the most frequent diagnosis, followed by ADHD, ASD, DLD, and DCD. A quarter of diagnosed children had multiple conditions (Truter et al., 2025d).

Griffiths-III results confirmed significantly lower Developmental Quotients across all domains for the concern/diagnosis group, with the Foundations-of-Learning subscale most affected. A-TAC and SDQ scores showed similar patterns of elevated developmental and behavioural risk. Physical and perinatal data reflected high rates of preterm birth, low socioeconomic status, and maternal stress.

These findings correspond to international literature indicating that global developmental delay and overlapping NDDs are common in contexts of socioeconomic adversity (Bitta et al., 2021; Grantham-McGregor et al., 2007;

Lu et al., 2016; Richter et al., 2017; Walker et al., 2023) and remind that in such environments, developmental outcomes are mediated by social determinants and biomedical aetiologies. Alongside these risks, local environmental exposures warrant consideration. Emerging evidence from the Western Cape's Hex River Valley—the agricultural region that includes our study community—links higher postnatal pesticide biomarker levels to poorer executive function among school-age children and adolescents (Viglietti et al., 2026). While our preschool cohort was not tested for pesticide exposure, these findings indicate that background environmental exposures may form part of the local risk landscape for neurodevelopment. This contextual factor should be considered in future work and when designing primary-care pathways in farming areas

Interpretation of these results must, however, acknowledge methodological constraints. The Griffiths-III is not standardised for South-African populations and lacks formal Afrikaans translation, though assessment was conducted in Afrikaans by a fluent bilingual (home language Afrikaans) psychologist, using consistent translation and accepting equivalent colloquial responses in language-dependent items (e.g. the 'Vocabulary' subtest). The A-TAC, developed for older children, provided useful dimensional insights but requires further age-specific validation for preschool use.

5.5 FINAL CONSIDERATIONS

A central question arising from this research is how useful developmental screening can be in communities where access to intervention remains extremely limited. On the surface, screening without available treatment might appear futile. Yet in practice, it is precisely in these contexts that structured, evidence-informed screening holds great potential value. By creating awareness of developmental differences, initiating conversations between

caregivers and health staff, and generating a record of need, screening establishes the foundation for advocacy, awareness and incremental service development. Even when direct intervention is unavailable, recognising a child's developmental challenges can help families adjust expectations, access informal supports, and pursue educational accommodations.

These features of the ESSENCE-Q may potentially have contributed to its utility in this context. Its brevity and straightforward scoring system allowed administration by trained community members with limited prior experience in developmental assessment. The instrument's transdiagnostic structure, which considers a broad range of developmental domains rather than centering on single diagnostic categories, aligned with the generalist orientation of rural primary-health-care services. In practice, the process of administering the questionnaire also served a secondary function: it created an opportunity for dialogue between caregivers and screeners about child development, which may have supported awareness and reduced stigma surrounding developmental differences.

Taken together, these findings suggest that the ESSENCE-Q is feasible in this setting and potentially useful as a first-step, community-deliverable screener that opens developmental dialogue and identifies children who may require further attention. At the same time, the present results suggest that it should be treated as a point of departure rather than a finished solution: its psychometric performance in this population is modest, and its utility will depend on careful local adaptation, supervision, and linkage to second-tier evaluation and support. In other words, the tool appears promising as an entry point into developmental surveillance, but it requires refinement and system embedding to become reliably helpful at scale.

This potential usefulness, however, will only be meaningful if screening is embedded within primary-health-care processes rather than existing as isolated research or pilot activity. Embedding awareness of developmental risk into the daily routines of PHC nurses, ECD teachers, and community health workers ensures that early identification becomes part of routine child-health surveillance. Over time, this integration could form the backbone of a scalable early-development surveillance system in South Africa's rural districts.

More broadly, this programme of work indicates several core characteristics that support feasible and valid screening for neurodevelopmental problems among young children in resource-limited settings: community grounding through trusted local personnel and iterative consultation; simplicity and brevity to minimise literacy and time barriers; structured training and supervision with trauma debriefing for screeners; a two-tiered design that combines broad screening with assessment and targeted follow-up; continuity and referral mechanisms linking screening to care; and ethical reflexivity to ensure that screening benefits families rather than creating unmet expectations.

5.6 CONCEPTUAL AND FRAMEWORK REFLECTIONS

The structure of the ESSENCE-Q, while simple to administer, reflects an underlying conceptual orientation that integrates overlapping developmental domains and supports consideration of the child's functioning as a whole. In constrained systems, this supports resource-sensitive prioritisation of care. The approach echoes the WHO's International Classification of Functioning, Disability and Health (ICF) framework and its adaptation into the "F-Words for Child Development" (Function, Family, Fitness, Fun, Friends, and Future) (Rosenbaum & Gorter, 2012; Smythe et al., 2020). Both emphasise participation and capability over deficit. Combining ESSENCE with these

models could help LMIC services move from diagnostic scarcity toward inclusive, family-centred developmental support.

5.7 LIMITATIONS AND FUTURE IMPLICATIONS

This programme of research has several limitations that must be acknowledged.

Firstly, all empirical work was undertaken in one rural community in the Western Cape, and the findings may not be generalisable to other regions or linguistic groups. The contextual and relational factors that enabled feasibility in De Doorns may not be replicable elsewhere without similar community engagement. Validity measures obtained for the ESSENCE-Q apply only to the Afrikaans translation and may not be valid in other communities with different contextual factors and population demographic.

Secondly, the implementation evaluation was limited to feasibility and acceptability. Future research should incorporate formal cost, sustainability, and integration analyses to inform scale-up. The evaluation of mothers' experiences was constrained by the length of time that had elapsed between screening and administration of the feedback questionnaires, largely due to unforeseen difficulties in tracing participants after the screening phase. Consequently, only mothers who attended assessment and received feedback were able to provide responses. This may have introduced bias, as their views were likely influenced by their experiences of the overall process rather than the screening component alone, despite efforts to clarify this distinction at the time. Qualitative interviews with mothers would likely have yielded richer, more nuanced insights into their experiences.

Thirdly, tool-related limitations include the absence of local norms and formal translations for some of the instruments used, most notably the Griffiths-III. Unfortunately, the reality is that in many LMIC countries, local norms for such widely used standardised tools do not exist. While the A-TAC has been translated for the purpose of the present study and caregiver perceptions examined (Nel & Kafaar, 2022), no local norms exist, and available Swedish norms are for slightly older children.

Fourthly, as screening relied on caregiver report, results are susceptible to bias from limited developmental awareness, recall inaccuracy, and social desirability. Similarly, trauma exposure and caregiver distress may have confounded reporting and child presentation.

Finally, the study design was cross-sectional and descriptive, precluding any inference about developmental trajectories or intervention effects. Longitudinal data would allow assessment of screening stability, child outcomes, and service engagement over time.

To strengthen this work, several interrelated factors are recommended. This would require a foundation of community grounding, achieved through the involvement of trusted local personnel and ongoing consultation with families to build trust and understanding. Screening instruments must be simple and brief to accommodate time constraints and varying literacy levels, while those administering them need structured training, supervision, and access to trauma debriefing. A two-tiered model, combining broad initial screening with more focused follow-up assessments, enhances both efficiency and accuracy. Continuity of care and clear referral mechanisms are essential to link screening to available services, however limited these may be. Finally, the process must be underpinned by ethical reflexivity, ensuring that screening generates

genuine benefit for families and does not create unrealistic expectations or unaddressed needs.

6 CONCLUSION

The studies comprising this research programme yield four primary conclusions.

Firstly, the scoping review of published studies on neurodevelopmental screening among children aged 2–8 years in sub-Saharan Africa (Paper I) revealed three interrelated priorities. There is an urgent need for simple, practical, and contextually appropriate screening instruments capable of capturing the broad range of NDDs that occur in this age group. Equally critical is the development of pragmatic strategies to support their use—such as low-cost, accessible, and potentially digital platforms—and for coherent policy mechanisms to bridge the gap between community-based screening and limited specialised healthcare in structurally disadvantaged settings.

Secondly, the feasibility study (Paper II) demonstrated that, with thorough preparation, adequate resourcing, and structured engagement, the use of key community members to facilitate ESSENCE-Q administration is both achievable and sustainable. Feasibility, however, is dependent on appropriate neurodevelopmental training, consistent supervision, and the provision of psychological support for those conducting screening in high-adversity contexts. Equally, the mother–child pair at the centre of the process requires sustained guidance, access to support services, and clarification of core developmental concepts to ensure that screening leads to meaningful engagement rather than isolated identification.

Thirdly, the validation study (Paper III) found that the ESSENCE-Q achieved moderate sensitivity and PPV in this context but demonstrated lower specificity and NPV. Consequently, while the tool can reliably confirm the need for referral to specialist neurodevelopmental assessment, it cannot safely

exclude referral without professional oversight and supervisory interpretation. The results suggest that the ESSENCE-Q is best positioned as an initial, broad-based screener within a two-tiered model of assessment, to be followed by more detailed, locally validated instruments.

Fourthly, the clinical characterisation study (Paper IV) identified a high prevalence of global developmental delay and overlapping developmental difficulties within the research cohort—findings consistent with international evidence linking socioeconomic disadvantage to cognitive and developmental risk. These concerns were not always reflected in formal DSM-5 diagnoses, highlighting the limits of categorical frameworks in such contexts. Notably, a quarter of children who received a diagnosis had more than one, underscoring the intertwined and overlapping nature of neurodevelopmental concerns. These findings argue less for diagnostic precision and more for a screening approach that recognises developmental concern as a continuum requiring early and holistic response. This perspective is supported by robust evidence demonstrating the long-term developmental, educational, and cost-efficiency benefits of early identification and intervention for children and families.

Finally, the four studies confirm that broad-based, community-embedded screening for neurodevelopmental concerns is both possible, valuable and needed in structurally disadvantaged settings. They also demonstrate that feasibility and utility depend on local contextual adaptation, supported human-resource capacity, and the integration of screening within primary-health-care processes. It also shows that while the ESSENCE-Q is feasible, acceptable, and potentially useful as a broad first-line screener, its psychometric performance in this setting is modest, indicating that the tool should be treated as an initial point of departure that requires ongoing local refinement and is best used when linked to structured second-tier evaluation. The findings

support the adoption of pragmatic, inclusive screening frameworks—such as ESSENCE—alongside broader system strengthening to ensure that awareness translates into early, sustained developmental support.

This programme of research contributes new empirical data to a largely under-explored field of African child-neurodevelopmental science. Recognising children "of concern" may be the most clinically and ethically meaningful goal in resource-limited contexts, where the scope for specialist diagnosis and intervention remains narrow. Sustained community engagement, trauma-informed supervision, and integration into primary-health-care structures are critical for any future scale-up. Further research should refine local adaptation of screening tools, strengthen intersectoral referral networks, and evaluate hybrid frameworks that merge ESSENCE principles with ICF approaches to promote participation and family empowerment.

Improving understanding of neurodevelopmental burden in structurally disadvantaged South-African settings has significance beyond clinical classification. While early-life programmes often (appropriately) prioritise physical health, nutrition, and survival, neurodevelopmental functioning represents a complementary dimension of child wellbeing that shapes later learning, participation, and longer-term opportunity. In this way, childhood neurodevelopment can be understood not only as an individual health outcome but also as a marker of future educational and psychosocial capacity within communities—and, cumulatively, of developmental potential at a national level. Strengthening early identification and support for neurodevelopmental risk may therefore contribute to longer-term human-capital outcomes, particularly in contexts where structural adversity constrains children's developmental trajectories from the outset.

The findings of this research point to several areas where further investigation would substantially strengthen the evidence base for early neurodevelopmental screening and support in structurally disadvantaged contexts.

Longitudinal follow-up of the children assessed in this programme is a critical next step. Such work would allow the stability and evolution of early developmental profiles to be examined over time. It would confirm whether diagnoses made during preschool years in this community sample, remain consistent; as well as clarify outcomes for those children identified as "of concern" but did not meet formal diagnostic criteria at the time of assessment. Reassessment at a later stage, using age-appropriate instruments, would provide important data on developmental trajectories and the predictive validity of early screening. Longitudinal data could also illuminate family and environmental factors that mediate developmental change.

Further research is needed to strengthen understanding of the validity and reliability of the ESSENCE-Q in South African and comparable contexts. This should include formal psychometric evaluation in larger, linguistically diverse samples, with rigorous forward–back translation procedures and blinded diagnostic verification. Item-level analyses and receiver-operating-characteristic comparisons could help determine whether alternative scoring thresholds or revised wording improve sensitivity and specificity. Response-process interviews conducted across linguistically and culturally diverse community settings would provide valuable insight into how caregivers interpret individual items and how locally embedded social and cultural norms shape response patterns. Such work is particularly important for clarifying how caregivers' local frames of reference—including peer comparisons and community norms—shape what becomes visible as a developmental "concern" in caregiver-report screening. This would contribute to refining the ESSENCE-

Q's measurement structure and to ensuring that observed results reflect genuine developmental concern rather than contextual or interpretive bias.

Comparative validation studies in comparable South-African and regional populations are also required. Side-by-side administration of the ESSENCE-Q and other broad-based screening tools—such as the PEDS and the NDST - would enable direct comparison of psychometric properties, user acceptability, and cultural applicability, and could guide recommendations for different service contexts. Such studies could also allow calibration of cut-off scores and refinement of translations to enhance diagnostic accuracy across diverse groups.

Future work should include qualitative exploration of caregivers' perspectives on child development, help-seeking, and access to services. Understanding mothers' experiences when they become concerned about their child's development, and their interactions with health and educational systems, would provide critical insights for designing interventions that are both responsive and acceptable. This may further ground early screening in the lived realities of families and inform strategies to strengthen developmental awareness within communities.

At a broader level, research should adopt implementation-science approaches to evaluate integration of screening within primary-health-care systems. This includes assessing cost, sustainability, fidelity, and outcomes following training of community personnel, as well as mechanisms for supervision and trauma support. Longitudinal and multisite designs, combined with policy engagement, will be essential to ensure that screening contributes not only to early detection but also to durable improvements in child development and family wellbeing across South Africa and the wider sub-Saharan region.

Ultimately, neurodevelopmental awareness and surveillance begin within the communities themselves. In rural and structurally disadvantaged areas such as the Breede Valley, community-based observation and response form the first line of developmental health care. Research in these settings should therefore be extended and sustained—not only to deepen understanding of neurodevelopmental risk and resilience, but also to build enduring local capacity for early recognition, support, and advocacy. Strengthening such community-level systems will be central to creating equitable pathways for all children to reach their developmental potential.

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APPENDICES

Appendix A: PRISMA-ScR Checklist (Paper I)

Appendix B: Search Strategies (Paper I)

Appendix C: Newcastle-Ottawa Quality Assessment Scales (Paper I)

Appendix D: Summaries of Newcastle-Ottawa Quality Assessment Scales Outcomes (Paper I)

Appendix E: Visual informed consent booklet (Paper II)

Appendix F: Mother's feedback rating questionnaire (Afrikaans) (Paper II)

APPENDIX A: PRISMA-SCR CHECKLIST

Table. PRISMA-ScR Checklist

Section	Item	PRISMA-ScR Checklist Item
Title	1	Identify the report as a scoping review.
Abstract		
Structured summary	2	Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Summary measures	13	Not applicable for scoping reviews.
Synthesis of results	14	Describe the methods of handling and summarizing the data that were charted.
Risk of bias across studies	15	Not applicable for scoping reviews.
Additional analyses	16	Not applicable for scoping reviews.
Results		
Selection of sources of evidence	17	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.
Characteristics of sources of evidence	18	For each source of evidence, present characteristics for which data were charted and provide the citations.
Critical appraisal within sources of evidence	19	If done, present data on critical appraisal of included sources of evidence (see item 12).
Results of individual sources of evidence	20	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.
Synthesis of results	21	Summarize and/or present the charting results as they relate to the review questions and objectives.
Risk of bias across studies	22	Not applicable for scoping reviews.
Additional analyses	23	Not applicable for scoping reviews.
Discussion		
Summary of evidence	24	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.
Limitations	25	Discuss the limitations of the scoping review process.
Conclusions	26	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.
Funding	27	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy documents).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

APPENDIX B: SEARCH STRATEGIES

i. PubMed Search Strategy 2024/03

#	Search	Results
#1	"Neurologic Manifestations "[Mesh] OR "Neurodevelopmental Disorders"[Mesh] OR "Fetal Alcohol Spectrum Disorders"[Mesh]	1,442,485
#2	"Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections"[Text Word] OR "Pediatric acute-onset neuropsychiatric syndrome"[Text Word] OR "PANS"[Text Word] OR neuropsychiatr*[Text Word] OR "sensory dysregulation"[Text Word] OR "developmental delay*"[Text Word] OR "developmental disability*"[Text Word] OR "developmental concern*"[Text Word] OR "brain development"[Text Word] OR "cognitive development*"[Text Word] OR "neural development"[Text Word] OR neurodevelopment*[Text Word] NOT hearing[Text Word] NOT ocular[Text Word] NOT vision[Text Word]	148,199
#3	#1 OR #2	1,552,849
#4	"Africa, Southern"[Mesh] OR "Africa South of the Sahara"[Mesh]	266,319

#5	Angola[Text Word] OR Benin[Text Word] OR Botswana[Text Word] OR Bobo-Dioulasso[Text Word] OR "Burkina Faso"[Text Word] OR Burundi[Text Word] OR Cameroon[Text Word] OR "Cape Verde"[Text Word] OR "Central African Republic"[Text Word] OR Chad[Text Word] OR Comoros[Text Word] OR Congo[Text Word] OR Brazzaville[Text Word] OR "Cote d'Ivoire"[Text Word] OR "Ivory Coast"[Text Word] OR Djibouti[Text Word] OR "Equatorial Guinea"[Text Word] OR Eritrea[Text Word] OR Ethiopia[Text Word] OR Gabon[Text Word] OR Gambia[Text Word] OR Ghana[Text Word] OR Guinea[Text Word] OR Bissau[Text Word] OR Kenya[Text Word] OR Lesotho[Text Word] OR Liberia[Text Word] OR Madagascar[Text Word] OR Malawi[Text Word] OR Mali[Text Word] OR Mauritania[Text Word] OR Mauritius[Text Word] OR Mozambique[Text Word] OR Namibia[Text Word] OR Niger[Text Word] OR Nigeria[Text Word] OR Rwanda[Text Word] OR "Sao Tome e Principe"[Text Word] OR Senegal[Text Word] OR Seychelles[Text Word] OR "Sierra Leone"[Text Word] OR Somalia[Text Word] OR "South Africa"[Text Word] OR South Sudan[Text Word] OR Sudan[Text Word] OR Swaziland[Text Word] OR Tanzania[Text Word] OR Togo[Text Word] OR Uganda[Text Word] OR Western Sahara[Text Word] OR Zaire[Text Word] OR Zambia[Text Word] OR Zimbabwe[Text Word] OR "Africa South of the Sahara"[Text Word] OR "Sub-Saharan Africa"[Text Word] OR "Southern Africa"[Text Word] OR "Subsaharan Africa*"[Text Word] OR "sub-sahara*"[Text Word] OR "subsahara*"[Text Word]	541,896
#6	#4 OR #5	548,567
#7	"mass screening"[Mesh]	145,347
#8	screen*[Text Word] OR "screening tool*"[Text Word]	1,101,000
#9	#7 OR #8	1,110,616

#10	"child"[MeSH Terms]	2,191,215
#11	"child*", "young children", infant, toddler, "Grade R"[Text Word] OR "Grade 1"[Text Word] OR "First Grade"[Text Word] OR "elementary school*"[Text Word] OR kindergarten*[Text Word] OR preschool[Text Word] OR pre-school[Text Word] OR "pre-primary school"[Text Word] OR "Gr 2"[Text Word] OR "Grade 2"[Text Word]	1,066,042
#12	#10 OR #11	2,247,688
#13	("2012/01/01"[Date - Publication] : "2023/03/01"[Date - Publication])	13,889,982
#14	#3 AND #6 AND #9 AND #12 AND #13	214

ii. Web of Science Searching Strategy 2024/03

#	Search	Results
#1	"Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR PANDAS OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatr* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* NOT hearing NOT ocular NOT vision (Topic)	181,394

#2	Angola OR Benin or Botswana OR Bobo-Dioulasso OR “Burkina Faso” OR Burundi OR Cameroon OR “Cape Verde” OR “Central African Republic” OR Chad OR Comoros OR Congo OR Brazzaville OR “Cote d'Ivoire” OR “Ivory Coast” OR Djibouti OR “Equatorial Guinea” OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR “Sao Tome e Principe” OR Senegal OR Seychelles OR “Sierra Leone” OR Somalia OR “South Africa” OR South Sudan OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Western Sahara OR Zaire OR Zambia OR Zimbabwe OR "Africa South of the Sahara" or "Sub-Saharan Africa" OR “Southern Africa” OR "Subsaharan Africa*" OR "sub-sahara*" OR "subsahara*" (Topic)	795,082
#3	"mass screening" OR screen* OR "screening tool*" (Topic)	1,216,285
#4	child* OR “young children” OR infant OR toddler OR “Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2" (Topic)	2,583,691
#5	#1 AND #2 AND #3 AND #4 AND 2012-01-01 to 2023-03-01 (Publication Date)	104

iii. PsycInfo Scoping Searching Strategy 2024/03

#	Search	Results
#1	"Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR PANDAS OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatr* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* NOT hearing NOT ocular NOT vision (Topic)	220,788
#2	Angola OR Benin or Botswana OR Bobo-Dioulasso OR "Burkina Faso" OR Burundi OR Cameroon OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoros OR Congo OR Brazzaville OR "Cote d'Ivoire" OR "Ivory Coast" OR Djibouti OR "Equatorial Guinea" OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR "Sao Tome e Principe" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR "South Africa" OR South Sudan OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Western Sahara OR Zaire OR Zambia OR Zimbabwe OR "Africa South of the Sahara" or "Sub-Saharan Africa" OR "Southern Africa" OR "Subsaharan Africa*" OR "sub-sahara*" OR "subsahara*" (Topic)	89,628
#3	"mass screening" OR screen* OR "screening tool*" (Topic)	155,014
#4	child* OR "young children" OR infant OR toddler OR "Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2" (Topic)	1,186,432
#5	#1 AND #2 AND #3 AND #4 AND 2012 to 2023 (Publication Date)	138

iv. SCOPUS Searching Strategy 2024/03

#	Search	Results
#6	(TITLE-ABS-KEY ("Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR pandas OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatr* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* AND NOT hearing AND NOT ocular AND NOT vision)) AND (TITLE-ABS-KEY ("mass screening" OR screen* OR "screening tool*")) AND (TITLE-ABS-KEY (child* OR "young children" OR infant OR toddler OR "Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2")) AND (LIMIT-TO (PUBYEAR , 2023) OR LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012)) AND (LIMIT-TO (AFFILCOUNTRY , "South Africa") OR LIMIT-TO (AFFILCOUNTRY , "Nigeria") OR LIMIT-TO (AFFILCOUNTRY , "Kenya") OR LIMIT-TO (AFFILCOUNTRY , "Uganda") OR LIMIT-TO (AFFILCOUNTRY , "Ethiopia") OR LIMIT-TO (AFFILCOUNTRY , "Tanzania") OR LIMIT-TO (AFFILCOUNTRY , "Ghana") OR LIMIT-TO (AFFILCOUNTRY , "Botswana") OR LIMIT-TO (AFFILCOUNTRY , "Zambia") OR LIMIT-TO (AFFILCOUNTRY , "Congo") OR LIMIT-TO (AFFILCOUNTRY , "Democratic Republic Congo") OR LIMIT-TO (AFFILCOUNTRY , "Zimbabwe") OR LIMIT-TO (AFFILCOUNTRY , "Mozambique") OR LIMIT-TO (AFFILCOUNTRY , "Rwanda") OR LIMIT-TO (AFFILCOUNTRY , "Benin") OR LIMIT-TO (AFFILCOUNTRY , "Malawi") OR LIMIT-TO (AFFILCOUNTRY , "Sudan") OR LIMIT-TO (AFFILCOUNTRY , "Cameroon") OR LIMIT-TO (AFFILCOUNTRY , "Gabon") OR LIMIT-TO (AFFILCOUNTRY ,	276

	"Angola") OR LIMIT-TO (AFFILCOUNTRY , "Gambia") OR LIMIT-TO (AFFILCOUNTRY , "Liberia") OR LIMIT-TO (AFFILCOUNTRY , "Burkina Faso") OR LIMIT-TO (AFFILCOUNTRY , "Central African Republic") OR LIMIT-TO (AFFILCOUNTRY , "Guinea") OR LIMIT-TO (AFFILCOUNTRY , "Madagascar") OR LIMIT-TO (AFFILCOUNTRY , "Mali") OR LIMIT-TO (AFFILCOUNTRY , "Mauritania") OR LIMIT-TO (AFFILCOUNTRY , "Senegal") OR LIMIT-TO (AFFILCOUNTRY , "Sierra Leone") OR LIMIT-TO (AFFILCOUNTRY , "Somalia") OR LIMIT-TO (AFFILCOUNTRY , "Togo"))	
#5	(TITLE-ABS-KEY ("Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR pandas OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatr* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* AND NOT hearing AND NOT ocular AND NOT vision)) AND (TITLE-ABS-KEY ("mass screening" OR screen* OR "screening tool*")) AND (TITLE-ABS-KEY (child* OR "young children" OR infant OR toddler OR "Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2")) AND (LIMIT-TO (PUBYEAR , 2023) OR LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012))	7, 380
#4	(TITLE-ABS-KEY ("Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR pandas OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatry* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* AND NOT	9,606

	hearing AND NOT ocular AND NOT vision)) AND (TITLE-ABS-KEY ("mass screening" OR screen* OR "screening tool*")) AND (TITLE-ABS-KEY (child* OR "young children" OR infant OR toddler OR "Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2"))	
#3	(child* OR "young children" OR infant OR toddler OR "Grade R" OR "Grade 1" OR "First Grade" OR "elementary school*" OR kindergarten* OR preschool OR pre-school OR "pre-primary school" OR "Gr 2" OR "Grade 2")	4,601,244
#2	TITLE-ABS-KEY ("mass screening" OR screen* OR "screening tool*")	1,973,169
#1	TITLE-ABS-KEY ("Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections" OR pandas OR "Pediatric acute-onset neuropsychiatric syndrome" OR "PANS" OR neuropsychiatr* OR "sensory dysregulation" OR "developmental delay*" OR "developmental disability*" OR "developmental concern*" OR "brain development" OR "cognitive development*" OR "neural development" OR neurodevelopment* AND NOT hearing AND NOT ocular AND NOT vision)	373,058

APPENDIX C: NEWCASTLE-OTTAWA QUALITY ASSESSMENT SCALES

i. NEWCASTLE-OTTAWA SCALE ADAPTED FOR CROSS-SECTIONAL STUDIES

Note*: A study can be awarded a maximum of one star for each numbered item within the Selection and Outcome categories. A maximum of two stars can be given for Comparability.*

Selection

1. Representativeness of the sample
   a. Truly representative of the average in the target population ★ (random sampling)
   b. Somewhat representative of the average in the target population★ (non-random sampling)
   c. Selected group of users / convenience sample
   d. No description of the sampling strategy
2. Sample size
   a. Justified and satisfactory ★
   b. Not justified / no information
3. Non-respondents
   a. Proportion of target sample recruited attains pre-specified target or basic summary of non-respondent characteristics in sampling frame recorded. ★
   b. Unsatisfactory recruitment rate; no summary data on non-respondents.
   c. No information provided
4. Ascertainment of the risk factor ('exposure')
   a. Validated screening tool used, or tool was validated in the study ★★
   b. Non-validated screening tool used, but the tool is available or described ★
   c. No description of the screening tool

Comparability

1. The participants in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled for.

a. The study controls for the most important factor ★
b. The study controls for any additional factor ★

Outcome

1. Assessment of the outcome
   a. Independent blind assessment by experienced clinician ★★
   b. Unblinded assessment using objectively validated methods ★★
   c. Used non-standard or non-validated methods
   d. No description
2. Statistical test
   a. The statistical test used to analyse the data is clearly described, appropriate, and measures of association is presented, including confidence intervals and probability level (*p* value) ★
   b. The statistical test is not appropriate, not described or incomplete

We did not specify the most important confounding factor due to the heterogeneity of the studies reviewed; the primary factor was identified for each study individually.

ii. NEWCASTLE-OTTAWA QUALITY ASSESSMENT SCALE FOR COHORT STUDIES

Note*: A study can be awarded a maximum of one star for each numbered item within the Selection and Outcome categories. A maximum of two stars can be given for Comparability.*

Selection

1. Representativeness of the exposed cohort
   a. Truly representative of the average child in the community★
   b. Somewhat representative of the average child in the community ★
   c. Selected group of users

    d. No description of the derivation of the cohort
2. Selection of the non-exposed cohort
    a. Drawn from the same community as the exposed cohort ★
    b. Drawn from a different source
    c. No description of the derivation of the non-exposed cohort
3. Ascertainment of exposure
    a. Secure record ★
    b. Structured interview ★
    c. Written self-report
    d. No description
4. Demonstration that outcome of interest was not present at start of study
    a. Yes ★
    b. No

Comparability

1. Comparability of cohorts on the basis of the design or analysis
    a. Study controls for the most important confounding factor ★
    b. Study controls for any additional factor ★

Outcome

1. Assessment of outcome
    a. Independent blind assessment ★
    b. Record linkage ★
    c. Self-report
    d. No description
2. Was follow-up long enough for outcomes to occur
    a. Yes ★
    b. No
3. Adequacy of follow-up of cohorts
    a. Complete follow-up – all subjects accounted for ★
    b. Subjects lost to follow-up unlikely to introduce bias – small number lost - >70% follow-up. or description provided of those lost ★
    c. Follow-up rate < 70% and no description of those lost

d. No statement

iii. NEWCASTLE-OTTAWA QUALITY ASSESSMENT SCALE FOR CASE-CONTOL STUDIES

Note*: A study can be awarded a maximum of one star for each numbered item within the Selection and Outcome categories. A maximum of two stars can be given for Comparability.*

Selection

1. Is the case definition adequate?
    a. Yes, with independent validation ★
    b. Yes, e.g. record linkage or self-report
    c. No description
2. Representativeness of the cases
    a. Consecutive or obviously representative series of cases ★
    b. Potential for selection biases or not stated
3. Selection of controls
    a. Community controls ★
    b. Hospital controls
    c. No description
4. Definition of controls
    a. No history of disease (endpoint)★
    b. No description of source

Comparability

1. Comparability of cases and controls on the basis of the design or analysis
    b. Study controls for the most important confounding factor ★
    c. Study controls for any additional factor ★

Exposure

1. Assessment of exposure
    a. Secure record ★

    b. Structured interview where blind to case/control status ★
    c. Interview not blinded to case/control status
    d. Written self-report or medical record only
    e. No description
2. Same methods of ascertainment for cases and controls
    a. Yes ★
    b. No
3. Non-response rate
    a. Same rate for both groups ★
    b. Non-respondents described
    c. Rate different and no designation

APPENDIX D: SUMMARIES OF NEWCASTLE-OTTAWA QUALITY ASSESSMENT SCALES OUTCOMES

i. SUMMARY OF NEWCASTLE-OTTAWA SCALE QUALITY ASSESSMENT FOR CROSS-SECTIONAL STUDIES

Study author, date, country	SELECTION (maximum 5 stars)				COMPARABILITY (maximum 2 stars)	OUTCOME (maximum 3 stars)		RATING	QUALITY
	Representativeness	Sample size	Similarity of non-respondents	Ascertainment of risk factor		Outcome assessment	Statistical test		
Kakooza-Mwesige et al., 2014, Uganda	★	★	☆	★☆	★★	★★	★	8/10	Good
Bitta et al., 2021, Kenya	★	★	☆	★☆	☆☆	★★	★	6/10	Satisfactory
Kariuki et al., 2020, Kenya	★	★	★	★★	☆☆	★★	★	8/10	Good
Kind et al., 2017, Kenya	★	★	★	★★	★★	★★	★	10/10	Very good
Arinda et al., 2020, Uganda	★	★	☆	★★	★★	☆☆	★	7/10	Good
Mazibuko & Chimbari, 2020, South Africa	☆	☆	☆	★☆	★★	☆☆	★	4/10	Unsatisfactory
Venter et al., 2015, South Africa	☆	☆	☆	★★	☆☆	★★	★	5/10	Satisfactory
Du Toit et al., 2021, South Africa	★	★	☆	★★	☆☆	★☆	★	6/10	Satisfactory
Knox et al., 2018, South Africa	★	★	☆	★★	★	★★	★	8/10	Good

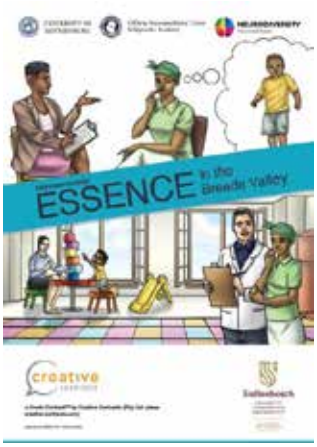
Descriptions of quality ratings: 9-10 = Very Good; 7-8 = Good; 5-6 = Satisfactory; 0-4 = Unsatisfactory

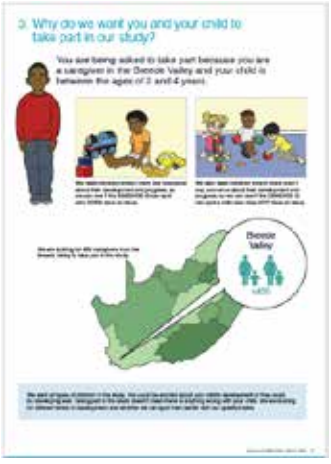
ii. SUMMARY OF NEWCASTLE-OTTAWA SCALE QUALITY ASSESSMENT FOR COHORT- AND CASE-CONTROL STUDIES

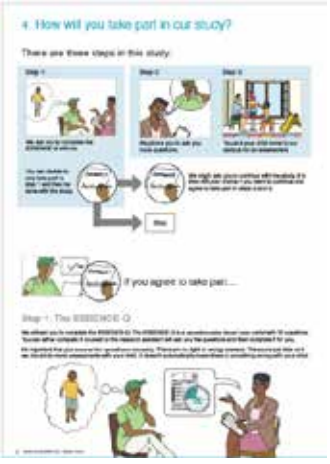
Study author, date, country	Study design	SELECTION (maximum 4 stars)	COMPARABILITY (maximum 2 stars)	OUTCOME (maximum 3 stars)	RATING	QUALITY
Devandra et al., 2013, Malawi	Case-control	★ Adequate case definition ★ Representativeness of cases ★ Selection of controls ★ Definition of controls	★ HIV ★ 2 siblings from same household	★Ascertainment of exposure ★Same method for cases & controls ☆ Non-response rate reported	8/9	Good
Shuffrey et al., 2021, South Africa	Part of cohort study	☆Representativeness of exposed ★ Selection of non-exposed ☆ Ascertainment of exposure ★Demonstrates that outcome not present at start of study	★ sex ★ maternal factors	☆ Assessment of outcome ★ Follow-up period long enough ☆ Adequacy of follow-up of cohorts	5 /9	Fair
Brittain et al., 2022, South Africa	Part of cohort study	★Representativeness of exposed ★ Selection of non-exposed ☆ Ascertainment of exposure ★Demonstrates that outcome not present at start of study	★ ACEs ★ Maternal mental health	☆ Assessment of outcome ★ Follow-up period long enough ★ Adequacy of follow-up of cohorts	7/9	Good

Descriptions of quality ratings: Good Quality: 3-4 stars in Selection; 1-2 stars in Comparability; 2-3 stars in Outcome/Exposure. Fair Quality: 2 stars in Selection; 1-2 stars in Comparability; 2-3 stars in Outcome/Exposure. Poor Quality: 0-1 star in Selection; 0 stars in Comparability; 0-1 star in Outcome/Exposure

APPENDIX E: VISUAL INFORMED CONSENT BOOKLET

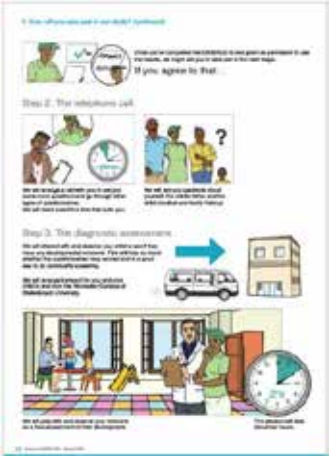



3. Why do we want you and your child to take part in our study?
You are being asked to take part because you are a caregiver in the Drakole Valley and your child is between the ages of 3 and 4 years.
Drakole Valley


4. How will you take part in our study?
There are three steps in this study:
If you agree to take part...

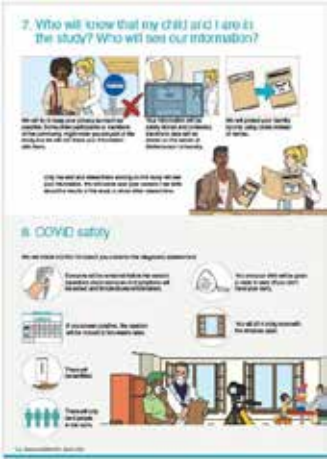

How to complete the ESSENCE-Q:
A. Fill in the details at the top.
B. Think about your child.
C. Tell us why?


There are the 12 categories we need you to think about:


If you agree to that...
Step 2: The telephone call
Step 3: The diagnostic assessment

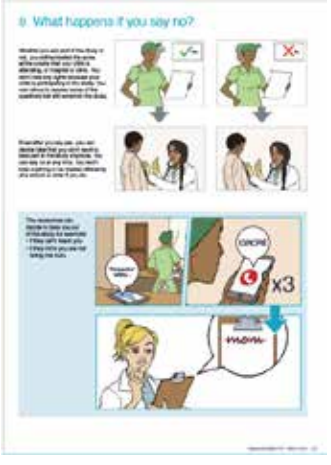
5. What will you get from taking part in this study?

6. What are the risks of this study?



7. Who will know that my child and I are in the study? Who will see our information?

8. COVID safety



9. What happens if you say no?

10. What happens now if you say yes?

We would also like permission to share the data we collect

11. What do I do if I have questions or problems?

You can contact:

APPENDIX F: MOTHER'S FEEDBACK RATING QUESTIONNAIRE (AFRIKAANS)

ESSENCE-Q PROJEK: DE DOORNS

Een van die doelwitte van hierdie studie was om te kyk of ons assistente uit die gemeenskap kan gebruik (soos die navorsings-assistant wat met u die ESSENCE-Q vraelys voltooi het) om gesinne in die Breede Vallei op 'n toepaslike en effektiewe manier te help 'screen' vir ontwikkelingsprobleme in kinders.

Ons wil graag weet hoe u die proses met die navorsings-assistente ervaar het. Ons sal dit baie waardeer as u hierdie kort vraelys kan voltooi.

- ➔ U terugvoer sal ons help om ons assistente beter voor te berei, sodat hulle ander beter kan help.
- ➔ U naam verskyn nêrens op die vraelys nie, so dit word heeltemal anoniem ingevul.
- ➔ Die assistente gaan ook nie die voltooide vraelyste sien nie.
- ➔ Deur hierdie vraelys te voltooi, gee u vir ons toestemming om die antwoorde in ons navorsing te gebruik (op 'n anonieme, algemene, opsommende manier).

MERK ASSEBLIEF BY ELKE STELLING HOE U OOR DAARDIE STELLING VOEL:

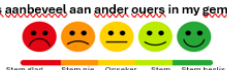
1) **Die navorsings-assistent was vriendelik en professioneel.**

2) **Ek het gemaklik gevoel met die navorsings-assistent.**

3) **Die assistent kon aan my verduidelik waaroor die vraelys gaan in taal wat ek maklik kon verstaan.**

4) **Die assistent het vir my verduidelik wat neuro-ontwikkelings probleme in kinders is, en watter tekens om voor op te let, in woorde wat ek kon verstaan.**

5) **Ek sal hierdie diens aanbeveel aan ander ouers in my gemeenskap.**



6) **Dit sal prakties en maklik wees om die ESSENCE-Q vraelys in my gemeenskap te gebruik.**

7) **Om die vraelys saam met die assistent te voltooi, het my meer geleer oor my kind se ontwikkeling.**

Enige ander opmerkings of terugvoer:

_____

_____

BAIE DANKIE!