Towards Naturalistic Developmental Behavioural Interventions for Autism in Africa: Nature and Context of Caregiver-Child Interactions in Low-Resource South African Environments

Submitted to the University of Cape Town in fulfilment of the requirements for the degree of MSc (Med) Neuroscience

Minkateko Ndlovu (NDLMIN004)

February 2022

Faculty of Health Sciences

Supervisors: Prof Petrus J de Vries, Dr Lauren Franz and Marisa Viljoen

PLAGIARISM DECLARATION

I, Minkateko Ndlovu (NDLMIN004), hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ACKNOWLEDGEMENTS

I would first like to thank my supervisors, Prof Petrus J de Vries, Dr Lauren Franz and Marisa Viljoen, for their advice, enduring support, encouragement and much-needed patience throughout my dissertation. I never knew a trio of supervisors was what I needed! Thank you for always being committed to being part of this journey with me.

To the ESDM (Early Start Denver Model) team, thank you for making me a part of the family. It was such a privilege to work with you all on this project. I have thoroughly enjoyed the experience.

Thank you to the CARA (Centre for Autism Research in Africa) team for their invaluable feedback, support and encouragement throughout my dissertation.

To Zahra Dawood, thank you for your encouragement and companionship throughout this journey, especially the coding.

Thank you to my siblings, Alecia and Amu, for your encouragement, unwavering support and love.

ABSTRACT

Background

Naturalistic developmental behavioural interventions (NDBI) are a group of evidence-based early interventions for autism spectrum disorders (ASD). Caregivers can be trained to deliver NDBI strategies during interactions with their young child with ASD. However, NDBI research predominantly comes from high-income countries, and the evidence base for NDBI in low/middle-income countries (LMICs) and across cultures is lacking. To understand the 'fit' of an NDBI approach in LMICs, it is crucial to understand and be able to measure the nature of interactions between caregivers and their children with ASD and the context wherein caregiver-child interactions occur. This study sought a) to evaluate the utility of a specific measure of caregiver-child dyadic interactions and b) to examine daily routines in which caregiver-child interactions occurred in low-resource South African contexts.

Methodology

Children with ASD (between 18-72 months old) and their ≥18-year-old caregivers were recruited under a larger project. Interactions of 21 caregiver-child dyads were video-recorded using a standardised parent-child interaction (PCI) protocol with two 6-minute-long free-play sessions (Part I: child explored the room and available toys while the caregiver remained seated; Part II: caregiver interacted with their child as they would at home). Two research-reliable raters rated the videos using 16 items from the Joint Engagement Rating Inventory (JERI), a 7-point Likert scale behavioural coding system.

Reliability and descriptive analyses were conducted. Structured interviews were conducted with ten caregivers using the Parent Survey of Home and Family Experiences (PSHFE) to explore the context of daily routines. Descriptive analyses were performed.

Results

For caregiver-child interactions, observer agreement for 12 of 16 items was reasonable, with weighted kappas (within 1 scale point) of 0.66-1, an estimated accuracy of 88-99%, and percentage agreements of 75-100% for all items. Ratings for items across Parts I and II of the JERI showed variability without any ceiling effects. Six items showed floor effects. Most caregiver item ratings were at the mid-point of the 7-point Likert scale. In Part II, children used more expressive language and paid more attention to their caregivers. On the PSHFE, most children participated daily in various child routines, play and early literacy activities with mothers as main partners. Most children never participated in spiritual and community activities, typically due to the child’s age, safety and other reasons not specified in interview response categories.

Conclusion

Reliability, floor/ceiling, behavioural and Part I vs Part II profiles suggested that the JERI, used for the first time in a South African context, has potential utility both to describe caregiver-child interactions and be used as an intervention outcome measure in LMICs. The PSHFE results provided contextual data of common daily activities into which NDBI strategies could be embedded to support child generalisation of skills in South Africa.

Keywords: ASD, NDBI, LMICs, JERI, caregiver-child interactions, daily activities, Parent Survey of Home and Family Experiences

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ABBREVIATIONS

ASD: Autism Spectrum Disorder

NDBI: Naturalistic Developmental Behavioural Interventions

LMICs: Low-and Middle-Income Countries

HICs: High-Income Countries

JERI: Joint Engagement Rating Inventory

PSHFE: Parent Survey of Home and Family Experiences

ESDM: Early Start Denver Model

ADOS-2: Autism Diagnostic Observation Schedule, Second Edition

DSM-5: Diagnostic and Statistical Manual of Mental Disorders

PCI: Parent-Child Interaction

M: Mean

SD: Standard Deviation

***Mdn*:** Median

***IQR*:** Inter-Quartile Range

KEY TERMS

Autism Spectrum Disorder (ASD)

Naturalistic Developmental Behavioural Interventions (NDBI)

Low- and Middle-Income Countries (LMICs)

Joint Engagement Rating Inventory (JERI)

Parent Survey of Home and Family Experiences

Caregiver-Child Interactions

Daily Activities

CHAPTER 1

1.1. Introduction

1.1.1. Background to the Dissertation

This dissertation examines the nature, quantification, as well as naturalistic contexts of interactions between young children with autism spectrum disorder (ASD) and their caregivers living in a low-resource South African environment. Chapter 1 provides background information on ASD in sub-Saharan Africa and the need for naturalistic developmental behavioural interventions (NDBI) for ASD in low/middle-income countries (LMICs). It also provides an outline of the overall study design. Chapter 2 explores the potential utility in a South African context of a specific behavioural coding system, the Joint Engagement Rating Inventory (JERI), to characterise the strategies and behaviours of caregivers and their young children with ASD during caregiver-child interactions. Chapter 3 explores the naturalistic contexts of caregiver-child interactions by describing the types of common activities that children with ASD participate in and the main partners involved in those activities with the child. Chapter 4 draws together findings from the entire study.

1.1.2. Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that emerges in early childhood and is characterised by persistent deficits in social interaction and communication and restricted, repetitive patterns of behaviour, interests, or activities (American Psychological Association, 2013). Deficits in social communication skills can be characterised by (1) difficulties in social interaction, engagement and the general exchange of social behaviours, (2) difficulties in understanding non-verbal communication, and (3) difficulties in forming and maintaining social relationships with peers and family members (APA, 2013; Hansen et al., 2018; Shulman et al., 2020). Restricted, repetitive patterns of behaviours and interests can include (1) stereotyped motor movements, use of objects and/or speech, (2) rigid patterns of behaviour and indicating difficulties with having small changes to routines, and (3) having unusually intense, fixated and narrow interests, and (4) sensory hypo- or hypersensitivity (APA, 2013; Shulman et al., 2020). Children with ASD have delayed or disrupted development of early social skills and display challenges in related areas such as acquiring receptive and expressive language skills (Mayo et al., 2013) adaptive behaviours, academic achievement and social skills (Sandbank et al., 2020). There is an increasing evidence-base that children with ASD can benefit from targeted interventions, such as naturalistic developmental behavioural interventions (NDBI), to learn foundational skills (Lord et al., 2021; Sandbank et al., 2020). However, the research that underpins NDBI predominantly comes from high-income countries (HICs), even though most people with ASD live in low- and middle-income countries (LMICs) (Franz et al., 2017; Lord et al., 2021). Therefore, the evidence base for NDBI in LMICs and across culturally and linguistically diverse communities is therefore lacking.

1.1.3. ASD in Sub-Saharan Africa

There are approximately 52.9 million children under the age of five with ASD and other developmental disabilities worldwide (Olusanya et al., 2018). About 95% of these children live in LMICs that are culturally and linguistically highly diverse (Olusanya et al., 2018). However, most information and research on ASD comes from HICs. Knowledge and evidence on the prevalence of ASD are increasing in HICs. Recent findings suggest the prevalence of ASD in children aged eight years in the USA to be 1.85% (Maenner et al., 2020). In Europe, an estimated ASD prevalence rate of 1.22% was proposed (Autism Spectrum Disorders in the European Union, 2018). However, the prevalence of ASD in low- and middle-income regions, such as sub-Saharan Africa, is unknown (Durkin et al., 2015; Franz et al., 2017; Ruparelia et al., 2016). While the burden of neurodevelopmental disorders such as ASD has increased substantially between 1990 and 2016 (Olusanya et al., 2018), few intervention services are available in these countries (Abubakar et al., 2016; Lord et al., 2021; Ruparelia et al., 2016). In sub-Saharan Africa, ASD is typically diagnosed late, leading to late intervention. Only a small number of ASD intervention studies have been conducted in sub-Saharan Africa (Franz et al., 2017; Franz et al., 2018; Hobson et al., 2007; Ruparelia et al., 2016). Considering the increasing burden of ASD in sub-Saharan Africa, there is a pressing need for early ASD interventions in this region and other LMICs (Bakare & Munir, 2011; Franz et al., 2017; Lord et al., 2021; Wannenburg & van Niekerk, 2018).

Individuals with ASD may require specialised services, and the lifetime costs (including costs such as family expenses and special education) to care for them are generally high (Clasquin-Johnson & Clasquin-Johnson, 2018; Erasmus, 2018; Peters-Scheffer et al., 2012; Rogge & Janssen, 2019; Zarafshan et al., 2019). Evidence suggests that early ASD intervention may lead to the alleviation of the severity of core symptoms, which may result in the decrease of substantial costs to families (Bryson et al., 2003;

Cidav et al., 2017; Guler et al., 2018; Kodak & Bergmann, 2020; Sandbank et al., 2020; Zarafshan et al., 2019). In HICs, most children with ASD receive support through early intervention and schooling services. However, in LMICs, many children face long waitlists and rely on support from their families (Lord et al., 2021). In South Africa, there is increased recognition of unmet needs for early ASD intervention (Franz et al., 2017; Guler et al., 2018; Schlebusch et al., 2020). South Africa has insufficient government schools for children with ASD; there are only nine government ASD schools nationally (Pillay et al., 2021; Schlebusch et al., 2020). The Western Cape Province has the highest concentration of ASD and special needs specific schools in South Africa (Pillay et al., 2021; van Schalkwyk et al., 2016). However, the province has a high demand for school placement, as many young children with ASD are on waiting lists for placement in Special Education Schools (Pillay et al., 2021, 2022; Schlebusch et al., 2020; Wannenburg & van Niekerk, 2018). The number of children with ASD on the waiting list has increased by 276% between 2012 and 2016, and this trend is expected to continue (Pillay et al., 2022; Schlebusch et al., 2020). In addition to the lack of public education services, other factors contributing to the lack of access to early intervention for ASD in South Africa include high inequality and poverty (Schlebusch et al., 2020). South Africa has been recognised as the most unequal country globally (Statistics South Africa, 2019; World Bank Group, 2018), and the majority of the country's population lives in poverty (Statistics South Africa, 2019). In the context of the socio-economic challenges and major gaps in services for children with ASD in LMICs, such as in South Africa, there is a clear need to identify scalable and sustainable models of support and intervention for children and families who live with ASD. Such models need to be evidence-informed, but also need to be accessible, acceptable, affordable and culturally-appropriate in the given context (Schlebusch et al., 2020). One of the models that has emerged as potentially feasible in LMICs and low-resource contexts is through the route of caregiver empowerment and skills training. Caregiver-mediated interventions could assist in addressing barriers to access to intervention and decrease the substantial costs to families by supporting caregivers and families of young children with ASD who are not in school and have little or no access to health services (Schlebusch et al., 2020). The general utility of parent/caregiver training may also allow for faster dissemination of services, particularly in underserved communities.

1.1.4. Naturalistic Developmental Behavioural Interventions (NDBI)

Various interventional approaches aim to address the core challenges associated with ASD (Sandbank et al., 2020). Among these approaches are NDBI which have emerged as a group of interventions with an evidence-base for early ASD intervention (Lord et al., 2021; Sandbank et al., 2020; Schreibman et al., 2015). NDBI comprises of empirically-based early intervention approaches for ASD that are underpinned by both behavioural and developmental theories of learning and development (Sandbank et al., 2020; Schreibman et al., 2015; Tiede & Walton, 2019). Examples of NDBI-based interventions include (but are not limited to) Incidental Teaching (IT), Pivotal Response Training (PRT), the Early Start Denver Model (ESDM), Enhanced Milieu Teaching (EMT), Reciprocal Imitation Training (RIT), Project ImPACT (Improving Parents As Communication Teachers), Joint Attention Symbolic Play Engagement and Regulation (JASPER), Social Communication/Emotional Regulation/Transactional Support

(SCERTS), and Early Achievements (Sandbank et al., 2020; Schreibman et al., 2015). NDBI target skills that are key precursors to language development and key foundational skills that promote learning by integrating the developmental domains of cognitive, social, and language skills (Bottema-Beutel et al., 2019; Mayo et al., 2013; Schreibman et al., 2015). Although the various NDBI-based interventions have procedural and technical differences, they share many common features, including a) using developmentally appropriate treatment goals that are individualised to each child, b) using natural contingencies (e.g., antecedent-response-consequence) to teach new behaviours and skills, c) involve shared control between the child and adult, and d) implementing interventions in naturalistic environments (Schreibman et al., 2015). NDBI are usually implemented within engagement activities between the child and an adult (the interventionist). Although interventionists of NDBI are usually trained professionals or therapists, NDBI may also be delivered by caregivers (Schreibman et al., 2015). Caregivers can be coached to deliver NDBI strategies to their children with ASD during daily shared interactions (Schlebusch et al., 2020; Schreibman et al., 2015). Caregiver coaching may increase the dissemination of NDBI and subsequently increase access to early intervention services in underserved settings like LMICs.

Caregivers who have received NDBI coaching can deliver NDBI strategies in shared interactions with their young child with ASD during familiar daily routines and activities (Sandbank et al., 2020; Schreibman et al., 2015; Tiede & Walton, 2019). Daily interactions and routines provide rich learning contexts for children (Schreibman et al., 2015), and caregiver implementation of strategies within these routines may enhance child learning in everyday life. Understanding how and in which activities caregivers and their children with ASD interact can assist in effectively implementing NDBI approaches.

1.1.4.1. Cultural and Geographical Limitations of NDBI

The behavioural and developmental research that underpins NDBI to date has largely been from high-income, monolingual, English-speaking, middle-socio-economic status participants (Fannin, 2017; Nielsen et al., 2017). By implication, the vast majority of ASD work, including NDBI research, is based on the behaviours and routines of study populations that are primarily composed of white, upper/middle-income families from WEIRD (Western, educated, industrial, rich, and democratic) backgrounds (Durkin et al., 2015; Nielsen et al., 2017). In an attempt to generate a more African-centric evidence-base, Franz and colleagues have started to collect data relevant to the planning and implementation of caregiver-mediated NDBI in South Africa (Franz et al., 2018; Guler et al., 2018; Makombe et al., 2019; Ramseur et al., 2019). Apart from the South African work, there are only three published studies that have examined the applicability and effectiveness of caregiver-coaching that is informed by NDBI in LMICs, only one of these studies implemented an NDBI and the other two implemented developmental interventions (Divan et al., 2019; Rahman et al., 2016; Zhou et al., 2018).

Coaching caregivers to deliver NDBI strategies is promising within low-resource LMIC contexts (Schlebusch et al., 2020). Caregivers can present teaching opportunities during typical daily interactions, experiences and routines with their child with ASD. Understanding what the interactions of children with ASD and their caregivers in LMIC contexts look like and understanding the natural settings of their daily interactions and routines is crucial for the adaption of NDBI in LMICs. This knowledge will contribute to understanding the relevance and ‘fit’ of NDBI in LMICs.

Taking together research on NDBI to date, there are two clear research domains where research in LMIC contexts is lacking: a) the nature and quantification of caregiver-child interactions, and b) information about the natural settings of daily interactions that are socio-culturally relevant.

1.1.5. Nature of Contexts of Caregiver-Child Interactions

Deficits in social interaction and social communication are among the core challenges of ASD. Children with ASD display social-communicative impairments such as difficulties in joint attention and affective engagement with others and understanding and expressing verbal and non-verbal communication (Bedford et al., 2012; Shumway & Wetherby, 2009; Sullivan et al., 2007). Caregiver-child interactions are among the core outcomes targeted by NDBI because caregivers can use NDBI strategies during interactions with their children with ASD, which can support behavioural and cognitive development in the child, which is mediated through improvements in joint attention, affective engagement and social communication skills (Bontinck et al., 2017; Mayo et al., 2013; Oono et al., 2013; Schreibman et al., 2015; Siller & Sigman, 2008). Furthermore, caregiver use of NDBI strategies during caregiver-child interactions allows caregivers to support the child in establishing shared interests (Oono et al., 2013; Siller & Sigman, 2008). Figure 1.1 illustrates a shared interaction between a child and their caregiver. The caregiver facilitates the child’s language by repeating the child’s expressive language and expanding it by adding one word (Frost et al., 2020).

Figure 1.1. Caregiver-Child Interaction with Caregiver Language Facilitation Strategies Duke Centre for Autism and Brain Development & the Centre for Autism Research in Africa, University of Cape Town, 2020. Reprinted with permission.

1.1.5.1. The Nature and Quantification of Caregiver-Child Interactions

The nature of caregiver-child interactions refers to the skills and behaviours that caregivers and their children with ASD use during caregiver-child interactions. Research on child play and development has reported cross-cultural variations in caregiver-child exchanges, such as eye contact and language use (Harrison, 2017; Kärtner, 2015). We, therefore, cannot assume that the skills and behaviours that NDBI target are the same in caregiver-child dyads living in culturally and linguistically diverse LMICs as those in non-LMICs. To adapt and understand the 'fit' of NDBI for LMICs, it is crucial to acquire knowledge about the skills and behaviours of caregiver-child dyads during caregiver-child interactions in LMICs. Knowledge about caregiver-child behaviour during interactions can be obtained through quantifying caregiver-child interactions. Caregiver-child interactions can be quantified using observational tools that measure caregiver-child interactions. Additionally, the quantification of caregiver-child interactions may assist in measuring change affected by NDBI and provide relevant information about whether an NBDI can induce change in the LMIC context in which it was delivered.

The Joint Engagement Rating Inventory (JERI) is a behavioural coding scheme designed to measure multiple aspects of caregiver-child interactions, especially at a time when children begin to acquire language from 12 months of age (Adamson et al., 2012). The JERI characterises joint engagement, communication dynamics and shared topics of caregiver-child interactions (Adamson et al., 2019; Suma et al., 2016). It consists of 32 items on a 7-point Likert scale that is detailed enough to provide significant and relevant reliability assessment and nuanced analyses (Adamson et al., 2012). The JERI has a well-established coding scheme and has been used in several research studies on early joint engagement and communication development in children with ASD, developmental delay and typical development (Adamson et al., 2012; Adamson et al., 2019; Hirsh-Pasek et al., 2015; Suma et al., 2016). The skills and behaviours measured by the JERI are in keeping with intervention targets within NDBI, such as social, language, and play skills

(Schreibman et al., 2015). The JERI is a measurement tool developed in a HIC setting. This is important to note because research on child play and development has reported cross-cultural variations in caregiver-child exchanges (Harrison, 2017; Kärtner, 2015). Observations of the JERI are based on western constructs, so they may not be culturally appropriate for caregiver-child dyads in LMIC contexts. The JERI has primarily been used in high-income settings. To the best of our knowledge to date, only one study has used a few JERI items in an African setting. Bard and colleagues (2022) used a few items from the JERI to examine the extent to which joint engagement is unique to humans by comparing behavioural forms or characteristics of joint engagement in human infants (from Cameroon and the Central African Republic) and chimpanzee infants. They found no species-uniqueness in the joint engagement characteristics. Definitions of items used in the Bard et al. (2022) study were based on initial versions of some child engagement state items in Bakeman and Adamson (1984) and not the definitions of items from the JERI in its current form (as per Adamson et al., 2012; 2020). There remains a scientific need to evaluate the potential utility of the JERI in culturally and linguistically diverse LMICs like South Africa. If proven useful, the JERI could become a helpful measurement tool in studies that assess the effects of early intervention on joint attention and language (Adamson et al., 2012).

1.1.5.2. Naturalistic Contexts of Caregiver-Child Interactions

Understanding the context in which intervention occurs is crucial for the implementation of NDBI in low-resource contexts (Schlebusch et al., 2020). Daily routines and interactions provide information about the naturalistic contexts in which caregivers implement NDBI strategies with their children with ASD. Therefore, to understand the relevance and 'fit' of NDBI in LMICs, we need to understand the natural settings of everyday shared routines and activities that children with ASD engage in, rather than assume that they will look like the everyday routines of children with ASD living in HIC settings.

Balton et al. (2019) conducted a mixed-methods study that described the family routines of typically-developing children in Soweto, South Africa, using an adapted Parent Survey of Home and Family Experiences (PSHFE). The PSHFE is a structured interview schedule that consists of closed and open-ended questions, developed to identify activities within the family context that are a source of children's learning opportunities (Balton et al., 2019; Dunst & Bruder, 1999). The interview schedule was developed for use in the United States of America and was adapted for the South African context by including contextually relevant activities in South Africa (Balton, 2009; Balton et al., 2019). In their study, Balton et al. (2019) found that children mostly participated in care, play and spiritual routines and that the types of activities and experiences that children participated in often depended on the family's beliefs, values, practices and resources. Children with ASD often have delayed and sometimes disrupted development in early social skills compared to their peers, who are typically developing and developmentally delayed (Shumway & Wetherby, 2009). As a result, children with ASD may not necessarily engage in the same types of activities or routines as typically-developing children or those with other developmental disabilities (Bandini et al., 2013). Understanding the common routines of young children with ASD in the South African context would be valuable to the existing literature. This study, therefore, set out to add to Balton and colleagues' (2019) findings (that only described the routines of typically developing children) by describing the routines of young children with ASD in a different South African environment.

Another qualitative study by Ramseur and colleagues (2019) provided a qualitative description of joint activity routines between young children with ASD and their caregivers in South Africa. These descriptions informed how NDBI strategies could be embedded in the South African context. Ramseur et al. (2019) found that caregivers participated in object-based play, sensory social routines, and family routines with their children. Caregivers identified these activities as the ideal joint activity routines within which they can use NDBI strategies (Ramseur et al., 2019). The present study sought to add to Ramseur et al. (2019) findings by using a quantitative approach to describe further the types of routines (i.e., the types of object-based play, sensory social routines, and family routines) that young children with ASD participate in with their caregivers/others in a low-resource South African environment. Acquiring this information will further assist in identifying the types of routines in which NDBI strategies can be embedded.

The studies conducted by Balton et al. (2019) and Ramseur et al. (2019) have provided valuable descriptions of caregiver-child interactions occurring in a South African context. However, research is lacking with a systematic quantitative approach to identifying and categorising the types of routines that young South African children with ASD participate in with their caregiver/others. Figure 1.2 demonstrates essential considerations that need to be understood to implement NDBI in low-resource environments. The focus of the present study was to understand ‘naturalistic’ contexts in which NDBI approaches can be implemented (the ‘N’) in LMICs, by collecting data to assist with understanding the nature of caregiver-child interactions and (2) the naturalistic contexts in which they occur in a low-resource South African environment. Acquiring this understanding can help us understand the 'fit' of NDBI in LMICs and facilitate adaptions to NDBI approaches that support the development of functional abilities in children with ASD in diverse, low-resource environments.

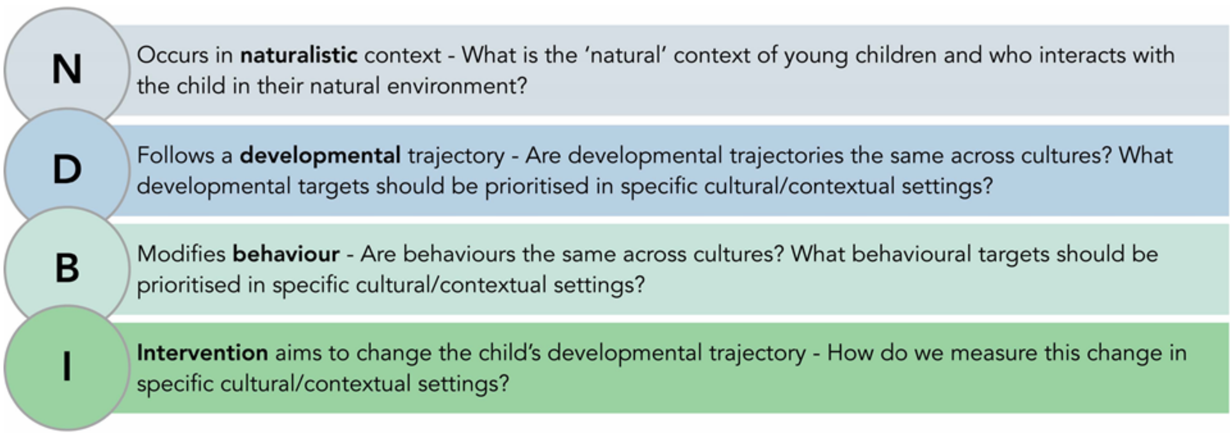

Figure 1.2. Key Considerations for Implementing Effective Naturalistic Developmental Behaviour Interventions (NDBI) in resource-limited contexts. From "Challenges and opportunities of implementing early interventions for autism spectrum disorders in resource-limited settings: A South African example," by Schlebusch, et al., 2020. Reprinted with permission.

1.2. Purpose of the Study

The overarching purpose of this study was to evaluate the usefulness and potential of a measurement tool (developed in the United States) to quantify and describe caregiver-child interactions and to examine the naturalistic contexts of caregiver-child interactions of families who live with ASD in a low-resource South African environment.

1.2.1. Study Aims

The study implemented two main aims to achieve the study purpose.

a. The study's first aim was to evaluate the utility of the Joint Engagement Rating Inventory (JERI) to quantify and characterise child engagement and behaviours, caregiver behaviours and dyadic interactions of young children with ASD and their caregivers.

b. The study's second aim was to describe the types of activities and routines of children with ASD and the main partners involved in the activities with the child.

1.3. Methodology

1.3.1. The Primary Project

This thesis was embedded in a larger primary project that sought to adapt a caregiver coaching version of the Early Start Denver Model (ESDM) (Dawson et al., 2010), an NDBI, for implementation by non-specialist early childhood development workers in a low resource South African setting (Franz et al., 2017; Ramseur et al., 2019; Guler et al., 2018; Makombe et al., 2019). Non-specialist Early Childhood Development (ECD) workers employed by Western Cape Education Department Schools were trained by professional ESDM therapists to conduct the NDBI-informed caregiver coaching sessions. The caregivers of children with ASD were coached using Community ESDM materials over 12 one-hour NDBI-informed coaching sessions (Makombe et al., 2019). The project's primary purpose was to provide fundamental knowledge on the validity of NDBI treatment targets and a better understanding of caregivers' abilities to acquire NDBI treatment strategies through non-specialist coaching.

1.3.1.1. Inclusion Criteria for the Primary Project

The inclusion criteria for caregiver-child dyads to be eligible for the primary project were as follows: (a) a child between 18 and 72 months of age, (b) the child had to meet the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM–5) criteria for ASD (APA, 2013), including scoring above ASD cut-off on the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) (Lord et al., 2012), (c) the caregiver was ≥ 18 years old, (d) the child and caregiver's family spoke isiXhosa, isiZulu, Afrikaans, or English (approximately 97% of all household languages spoken in the Western Cape province), (e) the child and caregiver's self-declared race/ethnicity was Black (including Black African, Coloured, and Indian people), (f) and the child and caregiver lived within an area served by the recruitment sites.

1.3.1.2. Exclusion Criteria

The exclusion criteria were (a) a child with a neurological disorder of known aetiology (for example, Fragile X syndrome), (b) a child with significant sensory or motor impairment that would preclude the use of the play materials, (c) a child with significant physical abnormalities that would interfere with participation in the intervention, (d) and a caregiver-child dyad unable to attend baseline and follow-up assessments and 12 coaching sessions in the primary study.

1.3.1.3. Recruitment and Enrolment

Eligible families with a child with ASD within the age of 18-72 months were identified by two Western Cape Education Department Schools. These schools had records of children diagnosed with ASD waiting for special education services. Families were invited to participate in the primary project by school staff. The primary project coordinator contacted those interested to explain the study. If the caregiver-child dyad met the criteria, the caregiver provided informed consent, and the dyad was enrolled.

1.4. Human Research Ethics

The primary project was granted ethical approval by the University of Cape Town (UCT) Human Research Ethics Committee (HREC468/2019) as well as the Duke Health Institutional Review Board (IRB Pr00103045). In the primary study, all participants received information about the study. All caregivers were adults and provided consent for themselves and their children for participation in the study. Assent was not relevant because all children were younger than six years of age. Participants were reimbursed for study-related expenses (ZAR100; ~US$8 for each study visit) and were provided with data vouchers (ZAR100; ~US$8).

The author of this dissertation was a research assistant on the primary project. For degree purposes, this study was a secondary analysis of data that was collected under the primary project. The degree protocol was reviewed following standard procedures in the Department of Psychiatry and Mental Health at the University of Cape Town and was reviewed and approved by the Faculty of Health Science Human Research Ethics Committee (HREC REF: 441/2021).

CHAPTER 2

2.1. The Nature and Quantification of Caregiver-Child Interactions

2.1.1. Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that can be identified from early childhood. Young children with ASD have challenges in social interaction, communication with others and repetitive or rigid behaviours (APA, 2013). There is increasing evidence that children with ASD can benefit from targeted early intervention to learn foundational skills and alleviate the severity of core ASD symptoms (Bryson et al., 2003; Kodak & Bergmann, 2020; Lord et al., 2021; Zarafshan et al., 2019). Naturalistic developmental behavioural interventions (NDBI) are a group of empirically-based early intervention approaches for ASD emerging as contemporary interventions for ASD (Lord et al., 2021; Sandbank et al., 2020; Schreibman et al., 2015). NDBI are derived from principles of applied behaviour and developmental science to enhance functional abilities in children with ASD (Schreibman et al., 2015). They target various developmental domains that young children with ASD have challenges in, such as early social communication, language, play and cognitive skills (Bottema-Beutel, 2016; Lord et al., 2021; Mayo et al., 2013; Sandbank et al., 2020; Schreibman et al., 2015). Various NDBI may have differences in procedural and technical approaches. However, they share essential common features, including implementing interventions within natural environments (Schreibman et al., 2015). Trained professionals can implement NDBI, but caregivers can also be trained/coached to implement NDBI strategies to their children with ASD during daily interactions and routines. Some examples of caregiver-mediated

NDBI include, but are not limited to, the Early Start Denver Model (ESDM) (Dawson et al., 2010; Rogers et al., 2012), Project ImPACT (Improving Parents As Communication Teachers) (Ingersoll & Wainer, 2013a, 2013b), and Joint Attention Symbolic Play Engagement and Regulation (JASPER) (Kaale et al., 2012; Kaale et al., 2014; Kasari et al., 2006; Kasari et al., 2010; Kasari et al., 2014). The implementation of NDBI by caregivers promotes the naturalistic contexts of the intervention because caregivers usually interact with the child in their natural environment. Caregivers can then present teaching opportunities while interacting with their young autistic child during familiar and naturally occurring routines and activities (Schreibman et al., 2015). The use of NDBI strategies during caregiver-child interactions can promote the development of early social communication, language and symbolic play skills in children with ASD (Lord et al., 2021; Sandbank et al., 2020).

Even though the majority of children with ASD live in low-and middle-income countries (LMICs) (Lord et al., 2021; Olusanya et al., 2018), research on NDBI predominantly comes from high-income countries (HICs), with participants from white, western, and upper/middle-socio-economic status backgrounds (Fannin, 2017; Nielsen et al., 2017). As a result, the current NDBI research is not representative of culturally and linguistically highly diverse populations, and the evidence base for determining whether and how NDBI can improve outcomes across cultures is lacking. Furthermore, developmental and behavioural research that forms the theoretical underpinnings of NDBI has overwhelmingly been conducted in Western contexts, with less than 3% of participants coming from Africa, Central and South America, Asia, and the Middle East (Nielsen et al., 2017). Therefore, NDBI may require adaption to ‘fit’ culturally and linguistically diverse LMIC contexts. Important questions remain about the relevance of NDBI for caregiver-child dyads living in culturally diverse LMICs, like South Africa (Ramseur et al., 2019). To adapt NDBI and assess whether they can improve child outcomes in LMICs, it is crucial to understand and quantify the nature of interactions between caregivers and their young children with ASD in this context. This study, therefore, set out to evaluate the utility of a specific tool, the Joint Engagement Rating Inventory (JERI), to collect data in a culturally and linguistically diverse South African context. The JERI is a tool that was developed in the United States to collect data on behaviours that caregivers and their children with ASD display during caregiver-child interactions.

2.1.1. The Joint Engagement Rating Inventory (JERI)

The JERI is a behavioural coding scheme designed to describe caregiver-child interactions. It can be used to characterise multiple aspects of caregiver-child interactions, including the child's joint engagement, behaviour and communication dynamics of the caregiver-child dyad and shared activities (Adamson et al., 2012; Adamson et al., 2018; Adamson et al., 2019). The inventory was designed to rate video-recorded observations of caregiver-child interactions that are made using a standardised parent-child interaction (PCI) protocol of up to 15 minutes long (Adamson et al., 2018). The JERI includes 32 items rated on a 7-point Likert scale across four categories: 1) child engagement state items, 2) child activity items, 3) caregiver activity items, and 4) dyadic interaction items (Adamson et al., 2012; Adamson et al., 2018). The JERI has been shown to be a reliable measure of caregiver-child interactions in HIC contexts. It has been used in several research studies to quantify the joint engagement and communication development in typically developing young children, those with developmental delay and those with ASD (Adamson et al., 2012; Adamson et al., 2019, 2021; Adamson et al., 2010; Conway et al., 2018; Hirsh-Pasek et al., 2015; Killmeyer & Kaczmarek, 2017; Salomone et al., 2021; Suma et al., 2016). The items in the JERI characterise behaviours that are in keeping with treatment targets within NDBI, for example, cognitive, social, language and play skills (Schreibman et al., 2015). The caregiver activity items in the JERI also align with the common fidelity elements of caregiver-mediated NDBI (Frost et al., 2020). Table 2.1 shows which JERI caregiver activity items align with NDBI common fidelity elements in a table reproduced from Frost et al. (2020). The alignment between the items in the JERI and the treatment targets and common elements of NDBI suggests that the JERI, theoretically, should be a suitable tool to measure child, caregiver-child and caregiver treatment targets for NDBI also in LMIC or other culturally and linguistically diverse contexts.

Table 2.1 *Match between the essential common elements of NDBI and the JERI caregiver activity items*

Essential Common Elements of NDBI (Frost et al., 2020)		Caregiver Activity Items in the JERI
Item	Description	Item
Face-to-face and on the child's level	Child and adult facing each other Child and adult on a similar level	Caregiver's communicative temptations, Caregiver scaffolding
Following the child's lead	Child and adult are both active participants in the child-chosen activity	Caregiver's following in on child's focus, Caregiver scaffolding
Positive affect and animation	Adult uses positive affect Adult matches affect to child's sensory needs	Caregiver's affect
Modelling appropriate language	Adult adjusts language to the child's developmental level	Caregiver's language facilitation, Caregiver scaffolding
Responding to attempts to communicate	Adult verbally responds to child's communication behaviours by repeating, clarifying, or expanding	Caregiver's language facilitation, caregiver scaffolding
Using communicative temptations	Adult creates situations to elicit communication from the child followed by a brief period of expectant waiting	Caregiver's communicative temptations, Caregiver scaffolding

Essential Common Elements of NDBI (Frost et al., 2020)		Caregiver Activity Items in the JERI
Item	Description	Item
Frequency of direct teaching episodes	Adult directs the child to demonstrate new or emerging skills	Caregiver's scaffolding
Quality of direct teaching episodes	Adult uses high-quality teaching strategies (e.g., clear instructions, when the child is motivated, contingent reinforcement).	Caregiver's scaffolding

Note. Reproduced from Identifying and measuring the common elements of naturalistic developmental behavioral interventions for autism spectrum disorder: Development of the NDBI-Fi by Frost et al., 2020, *Autism.* Copyright 2020 by Kyle Frost.

2.1.2. The Rationale of the Study

The JERI was developed in a HIC context, and studies that have used it, to date, have mainly been conducted in HIC contexts. However, research has reported cross-cultural variations in how caregivers and their young children interact. Therefore, it may be crucial to use the JERI in culturally and linguistically diverse LMICs like South Africa, which might have contextual implications. In order to evaluate any intervention studies in LMICs, appropriate tools are required to quantify the caregiver-child interactions of dyads who live in LMICs in culturally and contextually appropriate ways.

A first step would be to evaluate the potential use of the JERI in an LMIC context to quantify caregiver-child interactions in this context. Using the JERI in low-resource environments may assist in providing a broader understanding of caregiver-child interactions and the 'fit' of NDBI approaches within culturally and linguistically diverse LMIC contexts like South Africa. Therefore, this study aimed to 1) evaluate the utility of the JERI for use in South Africa by examining various aspects of reliability and validity of the tool, and 2) examine JERI observations of child engagement and behaviours, caregiver behaviours and dyadic interactions of young children with ASD and their caregivers to understand the 'fit' of NDBI in LMIC. We predicted that after formal training in the JERI, raters would achieve reliability for all the items in the JERI identified for the purpose of this study. We also predicted that the JERI could capture nuanced behaviours in children and caregivers during caregiver-child interactions with good face validity to ASD and ASD interventions, therefore suggesting a reasonable 'fit' of the JERI for use in NDBI in the South African context.

2.2. Methodology

2.2.1. Study Design

This study was a secondary analysis of data collected in a larger primary project. The study utilised a descriptive quantitative study design on the video data of caregiver-child interactions collected at the baseline assessment of an NBDI caregiver-coaching study. The video data were rated using the JERI behavioural coding system.

2.2.2. Research Procedures and Data Collection

2.2.2.1. Caregiver-Child interaction Video Recording Procedure

Caregiver-child interactions were video recorded, and a standardised PCI protocol was followed. The PCI consisted of two 6-minute-long free play sessions (Part I and Part II of the PCI) wherein the caregiver followed specific instructions with standardised materials. Video recordings of the caregiver-child interactions took place in a room with a camera and a one-way mirror. Figures 2.1 – 2.3 show the room setup and the materials used during interactions. The video recordings started after the caregiver-child dyad was introduced to the room and after the caregiver was given the following instructions about the PCI procedures: In Part I of the PCI, the caregiver was told to remain seated in a chair while the child moved freely about the room, explored the available toys and interacted with the caregiver. The caregiver was instructed to observe their child and not direct their attention. If the child approached and interacted with the caregiver, the caregiver could respond naturally to the child but had to try to remain seated. Part II of PCI began when the caregiver heard a knock on the one-way mirror. At this point, the caregiver could leave their chair and interact with their child as they typically would at home.

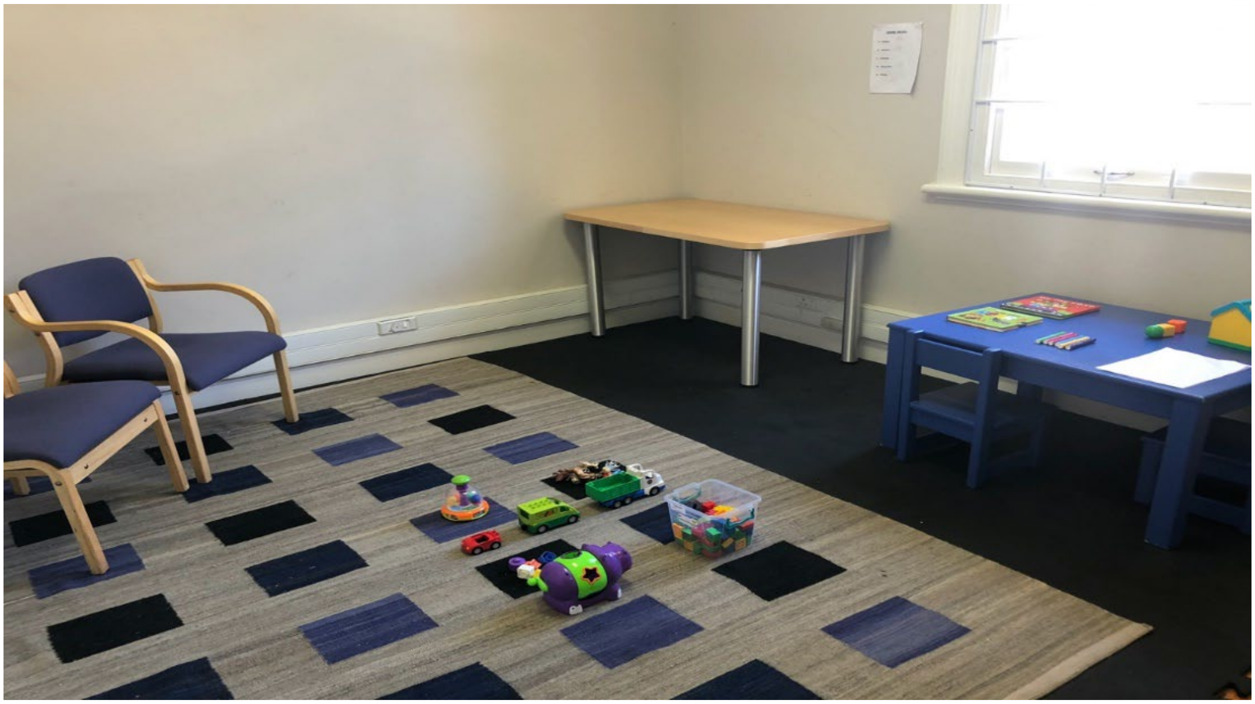

Figure 2.1. Parent-Child Interaction (PCI) Protocol Room Set-Up

Figure 2.2. PCI Protocol Floor Set-Up

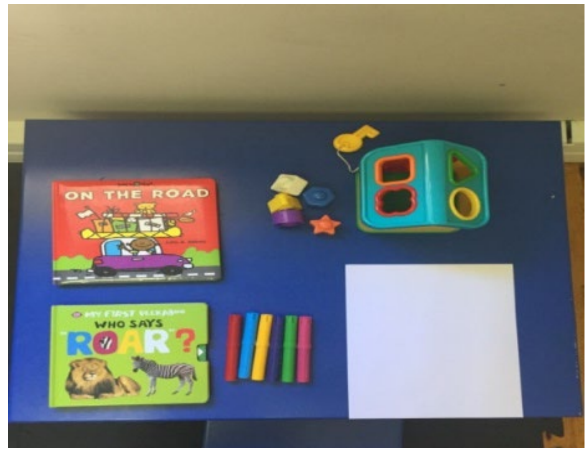

Figure 2.3. PCI Protocol Table Set-Up

2.2.2.2. Training on the Joint Engagement Rating Inventory for Reliability

Two Master's students (the author of this dissertation and a colleague) were trained over three months by a JERI master trainer to reach research reliability. In addition, the principal investigator received training to become a lead rater on the JERI within the study. Following training on the JERI, a total of 31 caregiver-child interaction PCI videos were independently rated by two trained raters. The 31 videos were a combination of the 21 videos recorded at baseline (used for this study) and ten videos recorded post-intervention (outside the scope of this study). The two raters were randomly assigned approximately 50% of the PCI-recorded videos (15 videos to one rater and 16 to the other). To assess reliability, the lead rater double-coded 16/31 randomly selected PCI videos (50% of each rater's videos). After each double-coded video, the raters and lead rater met to discuss ratings.

2.2.3. Measures

2.2.3.1. The Joint Engagement Rating Inventory (JERI)

As outlined, the study used the JERI to rate observations of the PCI-recorded caregiver-child interaction videos. In discussion with the developers of the JERI and before the study-specific JERI training, we identified 16 items that addressed the specific research aims of this study. These 16 items were used in the analysis of this study and were divided into four categories: child's engagement state items, child activity items, caregiver activity items, and dyadic interaction items (Adamson et al., 2018).

Child Engagement State Items. In the JERI, the child's engagement is observed as a state with a duration of at least 3 seconds long (Adamson et al., 2018). The child's interest and involvement with people, objects or events that are both real and symbolised (e.g., when a child uses objects to symbolise or represent other objects). The child's engagement is segmented into a series of mutually exclusive and exhaustive engagement states, including unengaged, object engagement and joint engagement (as well as person engagement and onlooking, which we did not code as items in this study) (Adamson et al., 2018). These states are rated on a 7-point Likert scale: a rating of 1 indicates a very low rating and no time spent in that engagement state, 4 is the midpoint indicating the moderate time and quality of episodes in an engagement state, and 7 indicates a very high rating and that the child spent almost all the time in that engagement state with high-quality engagement (Adamson et al., 2018). Table 2.2. describes these child engagement state items.

The child's joint engagement refers to a triadic state in which the child attends to or is actively involved in an object or event (real or symbolized) with which their caregiver is also actively involved. There is, therefore, a shared topic between the child and their caregiver during a state of joint engagement. Episodes of joint engagement come in three forms: supported joint engagement, coordinated joint engagement, and symbol-infused joint engagement. It is important to note that the child's supported joint engagement and coordinated joint engagement are mutually exclusive. Thus, a child cannot simultaneously be in a supported joint engagement state and a coordinated joint engagement state. However, a child can be in a symbol-infused joint engagement state while they are in supported joint engagement or coordinated joint engagement (Adamson et al., 2018). Table 2.3. provides a further description of the three forms of joint engagement.

Table 2.2. *Child Engagement State Items from the JERI*

Item	Description	Ratings		
		1=	**4=**	**7=**
Unengaged	Amount of time that the child does not display clear interest nor is actively involved with an object, specific person, and/or symbols	Almost always engaged with objects, people, and/or symbols	Unengaged for approximately a third of the scene (2/6 minutes)	Almost always unengaged
Object Engagement	Quality and quantity of the time the child is engaged in object play, exploring, or playing with an object(s) by themselves. The child is engaging with objects alone and not with another person.	No episodes of object engagement	Spends about a third of the scene in object engagement that is of moderate quality or briefly in object engagement in a highly striking manner	Frequently in rich and varied episodes of object engagement
Child's Joint Engagement	Overall quality and quantity of time in which the child is actively engaged with the same object(s) or event that the caregiver is focused on (a shared topic).	No episodes of the joint engagement state	Spends about a third of the scene in joint engagement that is of moderate quality or briefly in joint engagement in a strikingly high-quality manner	Frequently in rich and varied episodes of joint engagement

Note. Summarised from The Joint Engagement Rating Inventory (Technical Report 25, 2nd ed.) by L.B. Adamson, R. Bakeman and K. Suma, 2009, Georgia State University, Atlanta, GA. Copyright 2009 by Adamson and Bakeman, 2016.

Table 2.3. *Child's Joint Engagement State Items from the JERI*

Item	Description	Ratings		
		1=	4=	7=
Child's Supported Joint Engagement	The child is focused on a shared topic that the caregiver is influencing. However, during this period, the child does not acknowledge the caregiver's influence on the shared topic.	No episodes of the supported JE state	Spends about a third of the scene in supported JE that is of moderate quality, or briefly in supported JE in a highly striking manner	Frequently in rich and varied episodes of supported JE
Child's Coordinated Joint Engagement	The child is actively attending to both the shared topic and the caregiver. The child actively and repeatedly acknowledges the caregiver's involvement with their shared object or event. Coordinated JE is often evidenced by eye contact and/or repeated glances at the caregiver's face.	No episodes of the coordinated JE state	Spends about a third of the scene in coordinated JE that is of moderate quality or briefly in coordinated JE in a strikingly high-quality manner	Frequently in rich and varied episodes of coordinated JE

Item	Description	Ratings		
		1=	**4=**	**7=**
Child's Symbol-Infused Joint Engagement	The child is actively engaged in the same object or event as the caregiver and pays attention to symbols (e.g., using language and gestures that relate to the object or event in the shared activity).	No episodes of the symbol-infused JE state	Spends about a third of the scene in symbol-infused JE that is of moderate quality, briefly in symbol-infused JE in a strikingly high-quality manner	Frequently in rich and varied episodes of symbol-infused JE

Note. Summarised from The Joint Engagement Rating Inventory (Technical Report 25, 2nd ed.) by L.B. Adamson, R. Bakeman and K. Suma, 2009, Georgia State University, Atlanta, GA. Copyright 2009 by Adamson and Bakeman, 2016.

Child Activity Items. The child activity items capture the child's social-communicative acts, which encompass a range of verbal (e.g., expressive language and vocalisations), and nonverbal (e.g., eye contact and gestures) behaviours used in dyadic social interactions (Adamson et al., 2018). The child activity items selected for this study include the child's expressive language level and use, responsiveness to the partner's communication, and attention to the caregiver (see Table 2.4). A rating of 1 indicates that the child does not exhibit the social-communicative act (i.e., has no expressive language, does not respond to their caregiver's communication, or pays no attention to their caregiver). A rating of 4 is the mid-point of the scale, and it characterises a child who indicates moderate levels of social-communicative behaviours. A rating of 7 is very high, and it suggests that the child indicates these social-communicative acts frequently and at high quality (for the items that consider quality) (Adamson et al., 2018).

Caregiver Activity Items. The caregiver activity items capture caregiver behaviours that support and expand their child's activity and language. The caregiver activity items selected for this study include caregiver's scaffolding, following in on the child's focus, caregiver's affect, language facilitation and communicative temptations (see Table 2.5). A rating of 1 indicates that the caregiver rarely uses or has minimal use of the behaviours that support child activity and language. A rating of 4 indicates that the caregiver moderately uses supportive behaviours for the child's activity and language, with moderate quality. A rating of 7 is on the higher end of the scale and indicates that the caregiver frequently uses appropriate behaviours to support and expand their child's activity and language (Adamson et al., 2018).

Table 2.4. *Child Activity Items from the JERI*

Item	Description	Ratings		
		1=	4=	7=
Child's Responsiveness to Partner's Communication	Assesses how responsive the child appears to be to their caregiver as a communicative partner. It also assesses the child's overall pattern of attention and verbal and non-verbal communication.	Almost always resists or ignores bids	Responds to bids regularly but not continually	Complies with and anticipates almost every bid
Child's Expressive Language Level & Use	Assesses the child's use of expressive language. It does not need to be directed to the caregiver, and the production of words must be intelligible and intentional.	No expressive language	Produces many different single words during a scene with few or no word combinations	Fluent and frequent use of sentences
Child's Attention to Caregiver	Item assesses the frequency and quality of the child's active involvement with the caregiver. Attention may be demonstrated by the child looking directly at the caregiver's face, explicitly naming the caregiver, and following the caregiver's gestural prompts.	Does not pay attention to caregiver	Intermittently pays attention to caregiver	Frequently in rich and varied episodes of attending to the caregiver

Note. Summarised from The Joint Engagement Rating Inventory (Technical Report 25, 2nd ed.) by L.B. Adamson, R. Bakeman and K. Suma, 2009, Georgia State University, Atlanta, GA. Copyright 2009 by Adamson and Bakeman, 2016.

Table 2.5. *Caregiver Activity Items from the JERI*

Item	Description	Ratings		
		1=	**4=**	**7=**
Caregiver's Scaffolding	Item assesses how well and effectively the caregiver facilitates the child's performance and extends the child's activity by supporting the child's activities and guiding their actions. The goal is to provide learning opportunities that help the child engage in conversation or explore shared objects and events.	Provides minimal support for the child's communication or actions on objects	Provides moderate levels of support	Continually supports and extends the child's actions
Caregiver's Following in on Child's Focus	Assesses the caregiver's ability to track the child's current focus of attention and places their actions relative to the child's ongoing interest.	Rarely follows in on the child's current focus	Builds on the child's focus on a regular but not a continual basis	Almost continually joins and acts to sustain the child's interest
Caregiver's Affect	The influence of the caregiver's affect (i.e., emotions and mood) on the caregiver-child interaction and whether it impedes or	Tense, disruptive, or affectively flat, to the point of being expressionless and	Mellow or content as opposed to flat; affect does not impede	Smoothly modulated, appropriate, and serves to enhance

Item	Description	Ratings		
		1=	4=	7=
	enhances their communication with the child	subsequently very hard to read	communication, but neither does it enhance it	other modes of communication
Caregiver's Language Facilitation	Assesses the quality and quantity of the caregiver's language input that supports and extends the child's expressive and receptive language development. The caregiver's language input is dependent or responsive to the child's ongoing interest or focus of attention	Rare use of language facilitation strategies	Language scaffolding strategies are employed in one-third of the scene; or less time but of high quality; or more time of low quality	Continual use of a variety of language facilitation strategies
Caregiver's Communicative Temptations	Assesses the quality and quantity of the caregiver's efforts to elicit or sustain an interaction with the child through communication	Never makes any communicative temptations	Communicative strategies in 1/3 of the scene; or less time but of high quality; or more time of low quality	Continuous flexibility in making communicative temptations

Note. Summarised from The Joint Engagement Rating Inventory (Technical Report 25, 2nd ed.) by L.B. Adamson, R. Bakeman and K. Suma, 2009, Georgia State University, Atlanta, GA. Copyright 2009 by Adamson and Bakeman, 2016.

Dyadic Interaction Items. The dyadic interaction items capture the flow of the caregiver-child interaction and how the caregiver-child dyad shares an experience, topic, or object. These dyadic interaction items include fluency & connectedness and shared routines & rituals. A rating of 1 indicates no interaction between the dyad and that the dyad does not show an established pattern of behaviour. A rating of 4 indicates that the interaction exists, but it is not smooth, the dyadic exchanges are not balanced, and the use of familiar routines is not sustained. A rating of 7 indicates a frequent and long duration of routines and rituals, and the dyadic exchange is balanced and flows naturally back and forth. Table 2.6. provides the specific rating description for each dyadic interaction item.

Table 2.6. *Dyadic Interaction Items from the JERI*

Item	Description	Ratings		
		1=	**4=**	**7=**
Fluency & Connectedness	Captures information about the overarching flow of the interaction. Specifically, how well the dyad shares the interaction space in terms of initiating, responsiveness, connectedness between the dyad, and the fluency of the dyadic exchanges.	No interaction is established.	Interaction lacks smoothness and appears to be largely dominated by one partner.	Fluid and balanced interaction that is often sustained.
Shared Routines & Rituals	Quality and frequency of play routines and rituals that the dyad uses during an interaction. Specifically, how often and well the dyad uses prior knowledge or coordinated and scripted formats to structure joint engagement. Shared routines and rituals indicate established patterns of behaviour.	No evidence of routines and rituals.	Some shared routines and rituals are indicated but are not sustained and do not permeate the interaction.	Sustained, varied, and nuanced rituals and routines.

Note. Summarised from The Joint Engagement Rating Inventory (Technical Report 25, 2nd ed.) by L.B. Adamson, R. Bakeman and K. Suma, 2009, Georgia State University, Atlanta, GA. Copyright 2009 by Adamson and Bakeman, 2016.

2.3. Data Analysis

2.3.1. Reliability on the Joint Engagement Rating Inventory

We assessed reliability using Cohen's weighted kappa, a measure of agreement between two observed raters (inter-rater reliability) (Cohen, 1968). The weighted kappa considers the degree of disagreement between two raters (Sim & Wright, 2005). This study used a weighting scheme that regarded differences in JERI ratings between raters within 1 scale point as agreements (weighted as zero) and any differences of more than 1 scale point between raters as disagreements (weighted as 1). For example, if the first-rater rated a child a 4 for object engagement and the second-rater rated the child a 5, the two raters are in agreement by 1 scale point. However, if the first rater rated the child a 4, while the second rater rated a child 6, the two raters are considered to be in disagreement. The results were interpreted as follows: kappa values of 0 – 0.20 indicated no agreement, 0.21 – 0.39 as minimal, 0.40 – 0.59 as weak, 0.60 – 0.79 as moderate, 0.80 – 0.90 strong, and above 0.90 as almost perfect agreement (McHugh, 2012). Therefore, any weighted kappa values below 0.60 indicated inadequate agreement between the raters (McHugh, 2012). Observer estimated accuracy is the probability that a rater will correctly rate an event (Bakeman, 2018). This construct was used to determine whether a particular kappa value for an item was adequate (Bakeman, 2018). The goal for estimated accuracy in this study was 80%, as advised by Bakeman (2018).

2.3.2. Descriptive Quantitative Analysis of the Joint Engagement Rating Inventory

The data from the JERI were analysed using descriptive statistics, which include an examination of floor and ceiling effects, the frequency distribution of items (represented as histograms), mean values, standard deviations, median values (Mdn), and inter-quartile ranges (IQR). We also examined potential changes in JERI items between Parts I and II of the PCI. Floor and ceiling effects represent measurement limitations (Lewis-Beck et al., 2003; Salkind, 2010). Floor effects occur when a large concentration of participants receive a rating close to the lowest rating on a measurement (Lewis-Beck et al., 2003), and ceiling effects occur when a large proportion of participants reach the upper limits of a measure (Salkind, 2010). Ceiling effects decrease the likelihood that a measurement instrument has accurately measured what it intends to (Salkind, 2010). The mean and median are measures of central tendency, and they tell us what the midpoint of a group of ratings is (Tredoux & Durrheim, 2019). The mean provides the group average. However, a mean value can be influenced by extreme scores in a dataset. The median is a useful alternative to the mean, especially when computed for ordinal data like the JERI (Tredoux & Durrheim, 2019). The median describes the middle score in a ranked distribution of scores (Tredoux & Durrheim, 2019). The standard deviation and IQR are measures of variability and provide valuable information about how ratings are arranged around the mid-point. The standard deviation provides the average amount of variability in the dataset but is also sensitive to extreme values. On the other hand, the IQR summarises the variability of a dataset without the problem of outliers. The IQR is the difference between quartile 3 (Q3) and quartile 1(Q1) of the data (Tredoux & Durrheim, 2019).

2.4. Results

2.4.1. Participant Demographics

A total of 21 caregiver-child dyads participated in this study. Table 2.7 presents the participant demographics. The children were 28 – 64 months of age, and caregiver ages ranged from 25 – 60 years of age. Eighteen of the children were male, and three were female. Primary caregivers consisted of twelve mothers, seven fathers and two grandmothers. All the caregiver-child dyads were self-classified by caregivers as Black (including Black African, Coloured and Indian people). All participating children had a developmental history and an ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) (Lord et al., 2012) administered by a research reliable administrator. Nineteen children were administered module 1 of the ADOS-2, one Module 2 and one the Toddler Module. All children met the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) criteria for ASD (APA, 2013).

Table 2.7. *Participant Demographics*

Participant ID	Child				Caregiver		
	Age at study entry (months)	Gender	Ethnicity/Race	ADOS-2 Module	Age (years)	Primary caregiver	Ethnicity/Race
SAESDM34	61	Male	Coloured	Module1	33	Father	Coloured
SAESDM35	55	Male	Black African	Module 1	25	Mother	Black African
SAESDM36	61	Male	Indian	Module 2	36	Mother	Coloured
SAESDM37	64	Male	Black African	Module 1	35	Father	Black African
SAESDM39	30	Male	Black African	Module 1	29	Mother	Other
SAESDM41	64	Female	Black African	Module 1	37	Mother	Black African
SAESDM42	52	Male	Coloured	Module 1	38	Father	Coloured
SAESDM43	43	Male	Coloured	Module 1	35	Father	Coloured
SAESDM44	52	Male	Coloured	Module 1	30	Mother	Indian
SAESDM46	55	Male	Other	Module 1	60	Grandmother	Other
SAESDM47	31	Male	Coloured	Module 1	57	Grandmother	Coloured
SAESDM50	44	Male	Coloured	Module 1	36	Mother	Coloured

Participant ID	Child				Caregiver		
	Age at study entry (months)	Gender	Ethnicity/Race	ADOS-2 Module	Age (years)	Primary caregiver	Ethnicity/Race
SAESDM51	43	Male	Coloured	Module 1	30	Mother	Coloured
SAESDM52	54	Male	Coloured	Module 1	24	Mother	Coloured
SAESDM55	52	Male	Coloured	Module 1	33	Father	Coloured
SAESDM56	30	Male	Coloured	Module 1	33	Father	Coloured
SAESDM57	28	Female	Black African	Toddler module	41	Mother	Black African
SAESDM58	48	Male	Black African	Module 1	28	Mother	Black African
SAESDM60	36	Male	Coloured	Module 1	34	Father	Coloured
SAESDM61	60	Female	Coloured	Module 1	39	Mother	Coloured
SAESDM62	53	Male	Black African	Module 1	27	Mother	Black African

2.4.2. Reliability on the Joint Engagement Rating Inventory (JERI)

Table 2.8 shows the reliability results for the JERI ratings. The percentage agreements within 1 scale point for all items were 75-100%. Observer agreement for the following 12 items was reasonable: unengaged, object engagement, joint engagement, symbol-infused joint engagement, responsiveness to partners communication, expressive language level and use, attention to caregiver, following in on child's focus, caregiver's affect, communicative temptations, and fluency and connectedness. The weighted kappa values for the 12 items, within 1 scale point, were 0.66-1, and the observer accuracy was 88-99% (see Table 2.8).

There was low observer agreement for caregiver's scaffolding and caregiver's language facilitation, with weighted kappa values (within 1 scale point) of 0.49 and 0.39. Additionally, the observer accuracy for caregiver's scaffolding and caregiver's language facilitation was 76% and 73%, respectively, which was lower than our goal of 80%. Although the weighted kappa values for coordinated joint engagement and shared routines may suggest no agreement, we propose that the low weighted kappa values are due to low variability in the ratings. The observer accuracy for these two items was over 99%, and the percentage agreement within 1 scale point were 100% (see Table 2.8). The high observer accuracy and percentage agreement showed that the rater and lead rater were in agreement (within 1 scale point) for 100% of the time for coordinated joint engagement and shared routines and rituals. The low weighted kappa values for coordinated joint engagement and shared routines can be attributed to low variability in ratings, whereby raters primarily rated 1s.

Table 2.8. *Inter-rater reliability on the JERI*

JERI Item	Weighted kappa	Observer Estimated accuracy	Exact percentage agreement	Percentage agreement within 1 scale point
Child Engagement Items				
Unengaged	1*	>99%	91%	100%
Object Engagement	0.88*	95%	53%	94%
Child's Joint Engagement	0.66*	88%	63%	88%
Child's Supported JE	0.66*	88%	63%	88%
Child's Coordinated JE	0	>99%	94%	100%
Child's Symbol-Infused JE	0.72*	94%	63%	94%
Child Activity Items				

JERI Item	Weighted kappa	Observer Estimated accuracy	Exact percentage agreement	Percentage agreement within 1 scale point
Child’s Responsiveness to Partners Communication	0.81*	94%	75%	94%
Child’s Expressive Language Level & Use	0.93*	97%	78%	97%
Child’s Attention to Caregiver	0.74*	92%	47%	91%
Caregiver Activity Items				
Caregiver’s Scaffolding	0.49	76%	25%	75%
Caregiver’s Following in on Child’s focus	0.71*	89%	38%	88%
Caregiver’s Affect	1*	>99%	56%	100%
Caregiver’s Language Facilitation	0.39	73%	44%	75%
Caregiver’s Communicative Temptations	0.78*	94%	38%	94%

JERI Item	Weighted kappa	Observer Estimated accuracy	Exact percentage agreement	Percentage agreement within 1 scale point
Dyadic Interaction Items				
Fluency & Connectedness	0.77*	94%	44%	94%
Shared Routines & Rituals	0	>99%	94%	100%

Note. JE = Joint Engagement

* Indicates weighted kappa values of ≥.60 (reasonable agreement).

2.4.3. Parent-Child Interaction (PCI) Part I

PCI Part I is the first 6-minutes of the caregiver-child interaction, in which the child freely explores the room and available toys and interacts with the caregiver, who is asked to remain seated in a chair. We rated four JERI items in PCI Part I: unengaged, object engaged, expressive language level and use, and attention to caregiver. Results for PCI Part I are shown in Table 2.9 (descriptive statistics) and Figures 2.4-2.5 (frequency distributions).

As shown in Figures 2.4 and 2.5, none of the PCI Part I items showed ceiling effects; however, unengaged and expressive language level and use had floor effects. Children spent very little time unengaged, and a large proportion of the first 6-minute free-play session in object engagement with moderate quality (see Table 2.9 and Figure 2.4). Moderate quality object engagement refers to a child that engages in simple play like rolling a car back and forth or in combination play like puzzles or building blocks. Most children were rated on the lower end of the scale for expressive language, indicating little to no use of expressive language in the first 6-minutes of the PCI (see Table 2.9 and Figure 2.5a). Although there was a range of ratings for attention to caregiver, most children were rated on the lower end of the scale, indicating that children paid little attention to their caregiver (see Table 2.9 and Figure 2.5b).

Table 2.9. *Descriptive Statistics of Child Engagement and Activity Items (PCI Part I)*

JERI Item (PCI Part I)	*M (SD)*	*Mdn (IQR)*
Unengaged	1.43 (0.81)	1 (1 – 2)
Object Engagement	5.52 (1.20)	6 (5 – 6)
Child's Expressive Language Level and Use	1.86 (1.06)	2 (1 – 2)
Child's Attention to Caregiver	2.43 (1.50)	2 (1 – 4)

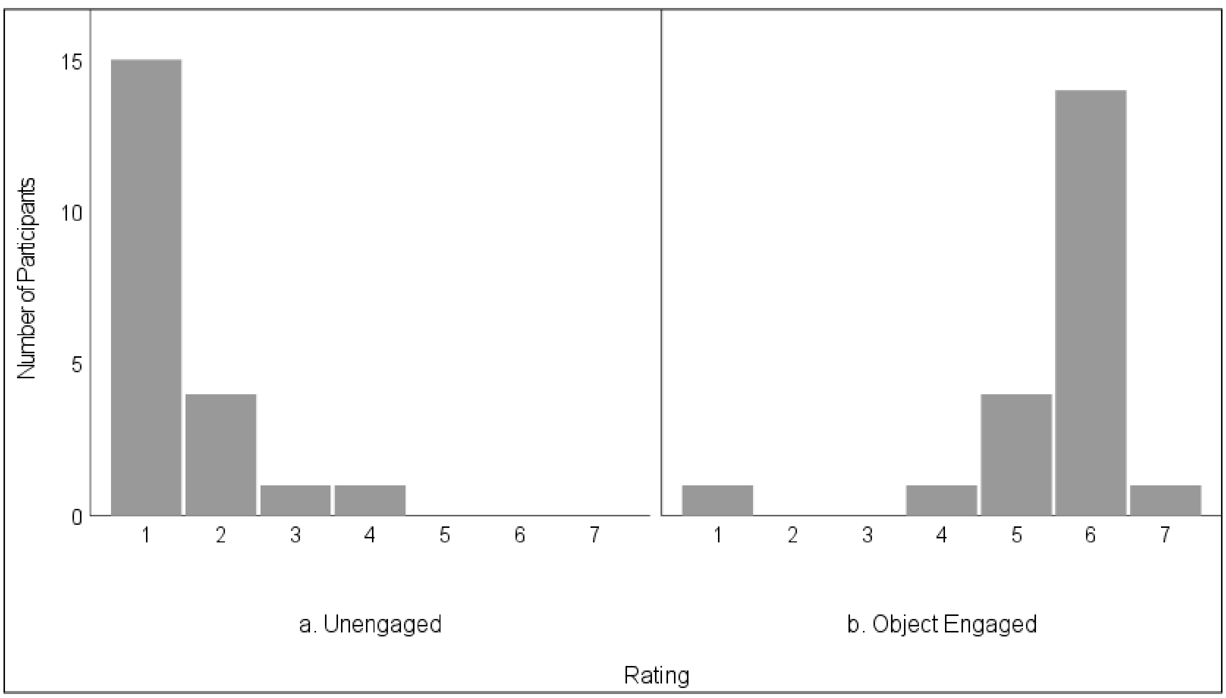

Figure 2.4. Histogram of Ratings for Child Engagement State Items in PCI Part I (N=21).

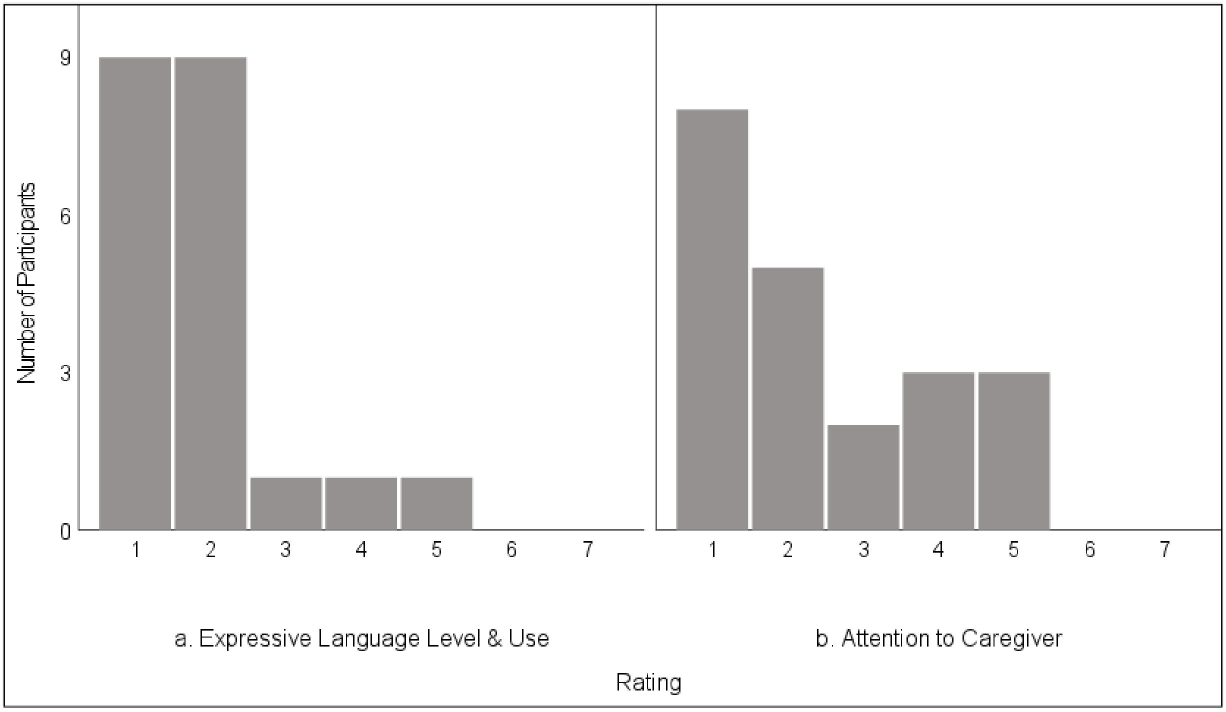

Figure 2.5. Histogram of Ratings for Child Activity Items in PCI Part I (N=21).

2.4.4. Parent-Child Interaction (PCI) Part II

PCI Part II is the 6-minutes of the caregiver-child interaction, where the caregiver was asked to leave the chair and interact with their child as they typically would at home using the standardised materials presented in the room. Sixteen JERI items were rated in PCI Part II. Results are shown in Tables 2.10-13 and Figures 2.6-2.10.

2.4.4.1. Child's Engagement State Items

The child engagement state items describe the child's attention to their caregiver, objects or events that are both real and symbolised (e.g., when a child uses objects to symbolise or represent other objects). Child engagement state items included unengaged, object engagement and child's joint engagement. Supported joint engagement, coordinated joint engagement and symbol-infused joint engagement items characterised different forms of joint engagement. None of the child engagement state items showed ceiling effects, but unengaged and coordinated joint engagement showed floor effects (see Figures 2.6 and 2.7). During PCI Part II, children spent a large proportion of the 6-minutes moving between object engagement and joint engagement (see Table 2.10 and Figure 2.6). Object engagement characterised a child who focused exclusively on exploring or playing with objects alone (and not focused on the caregiver). The child's joint engagement item characterised a triadic state whereby the child is engaged in the same objects or events in which their caregiver is actively involved. Figure 2.7*a* shows that a large proportion of the children's periods of joint engagement were supported, meaning the child and caregiver were engaged in the same object or event. However, the child did not notice that the caregiver was participating in or influencing their activity. The *Mdn* for coordinated joint engagement is 1 (see Table 2.10). The *IQR* is zero, indicating no variability in the ratings and that all the item ratings in the middle of the data set are the same (see Table 2.10). Most children were rated 1 for coordinated joint engagement, suggesting that children never actively acknowledged or noticed their caregiver during an episode of joint engagement by making explicit eye contact with them (see Table 2.10 and Figure 2.7b). Most children were rated a 1 for symbol-infused joint engagement, suggesting that children never paid attention to symbols when they were actively engaged in the same object or event as their caregiver (see Table 2.10 and Figure 2.7c). For example, a child that uses language and gestures that relate to the object or even in the shared activity would be considered to be in a state of symbol-infused joint engagement.

***Table 2.10**. Descriptive Statistics of Child Engagement State Items (PCI Part II)*

JERI Item	*M (SD)*	*Mdn (IQR)*
Child's Engagement Items		
Unengaged	1.48 (0.81)	1 (1 – 2)
Object Engagement	3.05 (1.16)	3 (2 – 4)
Child's Joint Engagement	4.90 (1.04)	5 (4.50 – 6)
Child's Joint Engagement State Items		
Child's Supported Joint Engagement	4.90 (1.04)	5 (4.50 – 6)
Child's Coordinated Joint Engagement	1.19 (0.51)	1 (1 – 1)
Child's Symbol-Infused Joint Engagement	1. 62 (0.92)	1 (1 – 2)

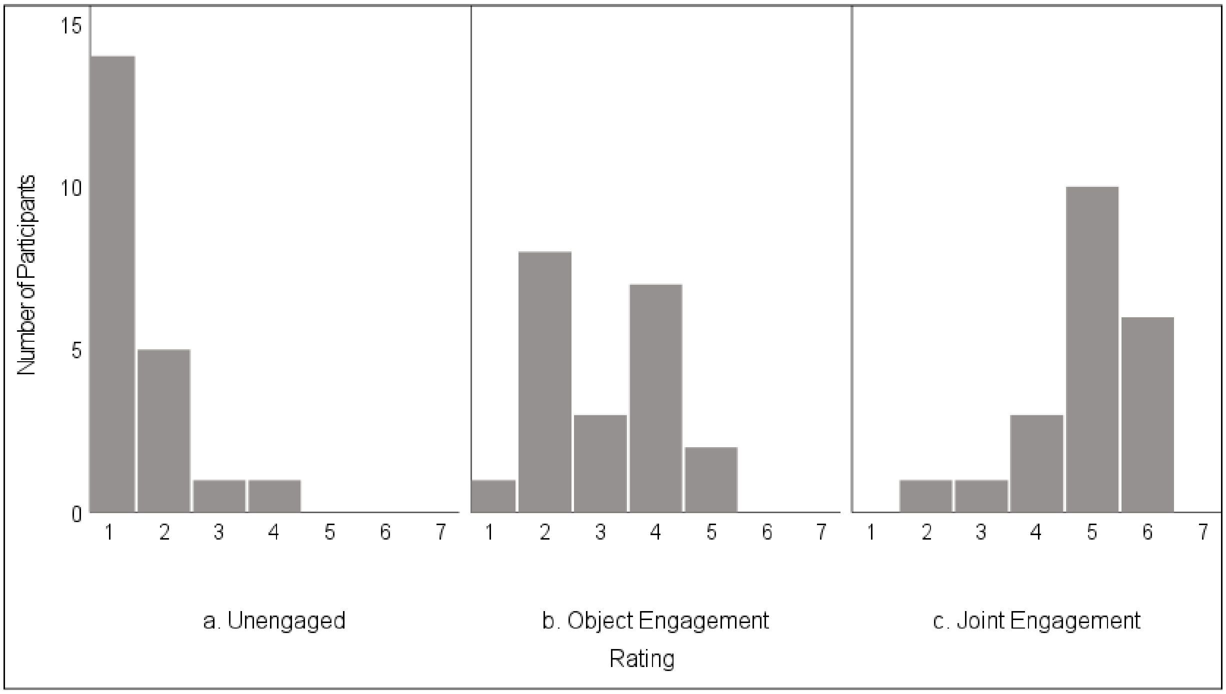

Figure 2.6. Histogram of Ratings for Child's Engagement State Items in PCI Part II (N=21).

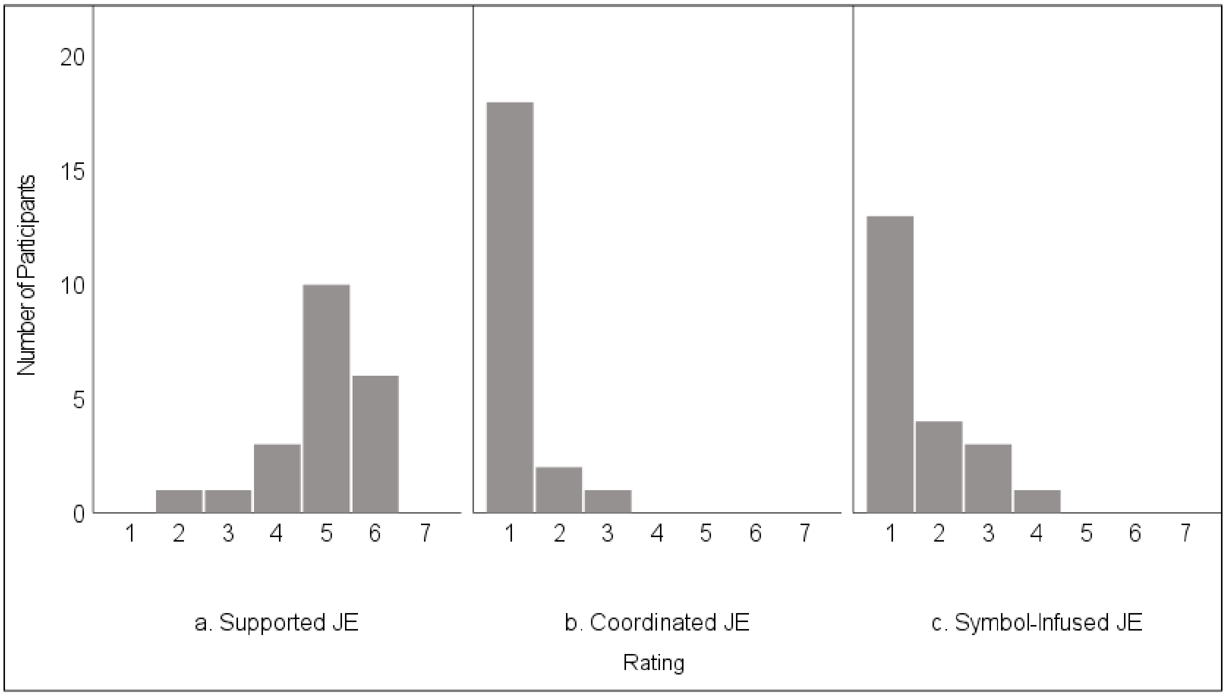

Figure 2.7. Histogram of Ratings for Child's Joint Engagement State Items in PCI Part II (N=21).

2.4.4.2. Child Activity Items

The child activity items captured the child's social-communicative acts and overall pattern of attention to their caregiver. These items included the child's responsiveness to partner's communication, expressive language level and use, and attention to caregiver. There was a range of ratings for the three child activity items, but with no floor or ceiling effects. The ratings for responsiveness to partner's communication were mainly around the midpoint of the scale (see Figure 2.8a), showing that the children did not continually respond to their caregiver's verbal and non-verbal communication. In PCI Part II, most of the children were rated on the lower end of the 7-point scale for expressive language level and use, with most ratings between 1-3 (see Table 2.11 and Figure 2.8b). These results showed that most children either used no expressive language (rating of 1), used about 1-4 different single words (rating of 2) or about 5–9 different single words (rating of 3). Children had varying degrees of attention to their caregiver, with ratings around the midpoint of the scale, showing that children's active involvement with their caregiver was irregular (see Table 2.11 and Figure 2.8c).

Table 2.11. *Descriptive Statistics of Child Activity Items (PCI Part II)*

JERI Item	*M (SD)*	*Mdn (IQR)*
Child's Responsiveness to Partner's Communication	4.19 (1.16)	4 (3 – 5)
Child's Expressive Language Level and Use	2.14 (1.27)	2 (1 – 3)
Child's Attention to Caregiver	3.57 (1.46)	4 (2.5 – 5)

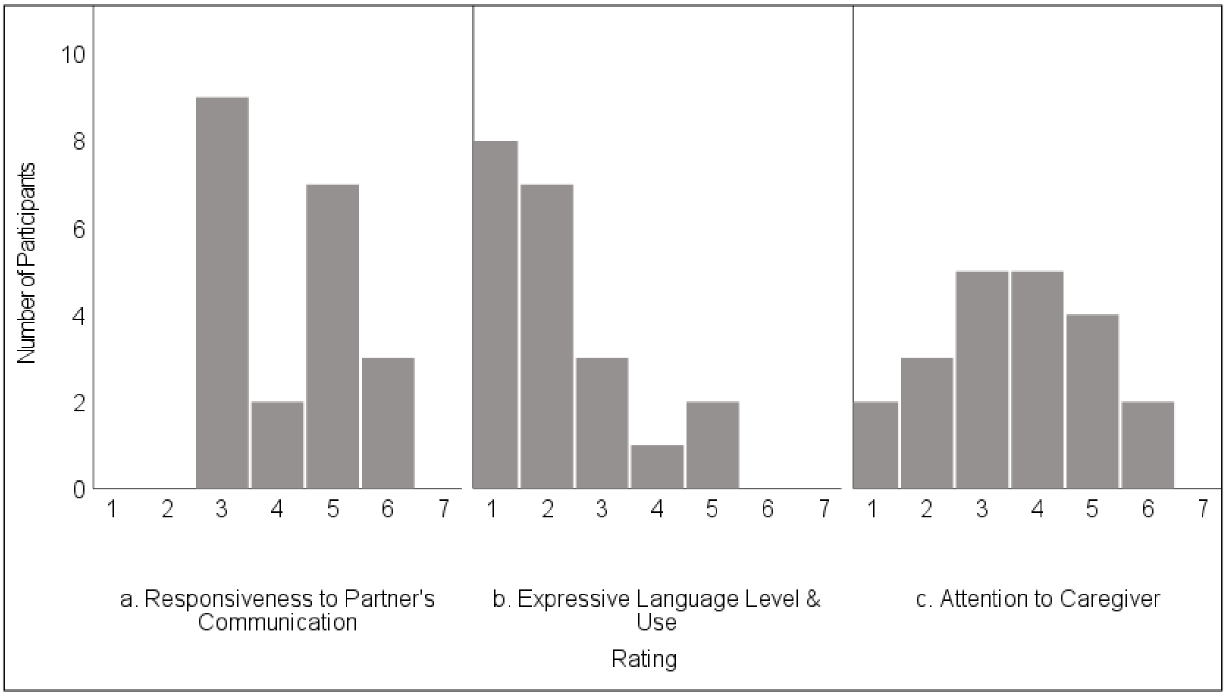

Figure 2.8. Histogram of Ratings for Child Activity Items (N=21).

2.4.4.3. Caregiver Activity Items

The caregiver activity items captured caregiver behaviours that may support and expand their child's activity, engagement, and language during an interaction. The caregiver activity items included scaffolding, following in on the child's focus, caregiver affect, language facilitation and communicative temptations. There were no floor or ceiling effects for any caregiver activity items. Table 2.12 (descriptive statistics) and Figure 2.9 (frequency distributions) show the results for the caregiver items. Most caregivers were rated to varying degrees at the midpoint of the scale for all caregiver activity items (see Table 2.12 and Figure 2.9). A rating of 4 for scaffolding shows that caregivers provided moderate levels of support for their children. A rating of 4 for following in on a child's focus shows that caregivers tracked and built on their children's focus of attention regularly but not continually. A rating of 4 for caregiver's affect suggests that the caregivers' affect was mellow and did not impede nor enhance communication with their children. A rating of 4 for language facilitation shows that caregivers had used language that may support their children's language use for about one-third of the 6-minutes (*Mdn* = 4), *IQR* = 2 – 5). A rating of 4 for communicative temptations shows that caregivers used communicative strategies to elicit or sustain an interaction with their children for approximately one-third of the 6-minutes.

Table 2.12. *Descriptive Statistics of Caregiver Activity Items (PCI Part II)*

JERI Item	*M (SD)*	*Mdn (IQR)*
Caregiver's Scaffolding	4.14 (1.35)	4 (3 – 5)
Caregiver's Following in on Child's Focus	4.24 (1.33)	4 (3 – 5)
Caregiver's Affect	4.10 (0.83)	4 (4 – 4.50)
Caregiver's Language Facilitation	3.62 (1.56)	4 (2 – 5)
Caregiver's Communicative Temptations	4 (0.83)	4 (3 – 4.50)

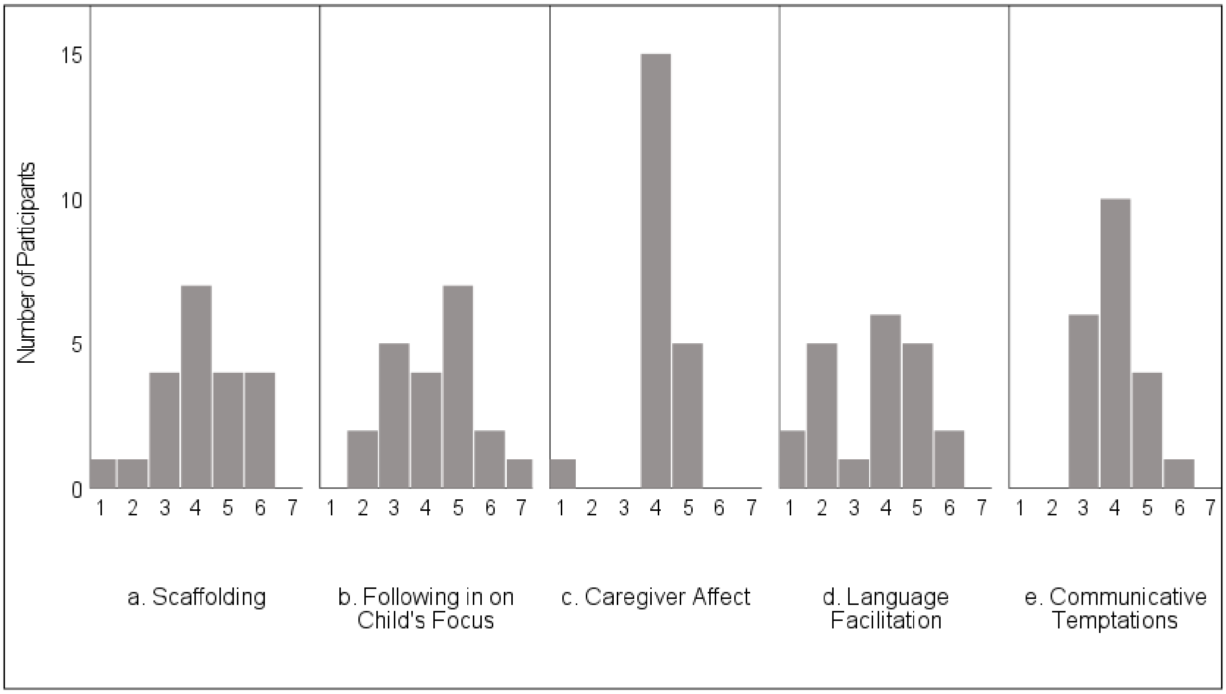

Figure 2.9. Histogram of Ratings for Caregiver Activity Items (N=21).

2.4.4.4. Dyadic Interaction Items

The dyadic interaction items captured information about the overall flow and structure of caregiver-child interactions. These items included fluency and connectedness as well as shared routines and rituals; the results are shown in Table 2.13 and Figure 2.10. There were no floor or ceiling effects for fluency and connectedness, but there were floor effects for shared routines and rituals. There was a range of ratings for fluency and connectedness. Most caregiver-child dyads were rated at the midpoint of the 7-point scale, suggesting several different interaction types as three components contribute to the overall rating for fluency and connectedness. In our study, a rating of 4 generally indicated that one partner in the dyad (usually the child) needed a considerable amount of support during the interaction (i.e., the objects and structure of the play and interaction were provided and arranged by one partner as the other partner lacked the skill). Most dyads were rated a 1 for shared routines and rituals (see Table 2.13 and Figure 2.10b). The standard deviation and *IQR* for shared routines and rituals are low (Table 2.13), which indicates low variability in the ratings and that all the item ratings in the middle of the data set are the same (also see Figure 2.10B). A rating of 1 for shared routines and rituals characterised a dyad that never showed established patterns of behaviour (i.e., behaviours that a dyad naturally uses at home, like sitting a particular way when reading a book).

Table 2.13. *Descriptive Statistics of Dyadic Interaction Items (PCI Part II)*

JERI Item	*M (SD)*	*Mdn (IQR)*
Fluency and Connectedness	4 (1)	4 (3 – 5)
Shared Routines and Rituals	1.19 (0.4)	1 (1 – 1)

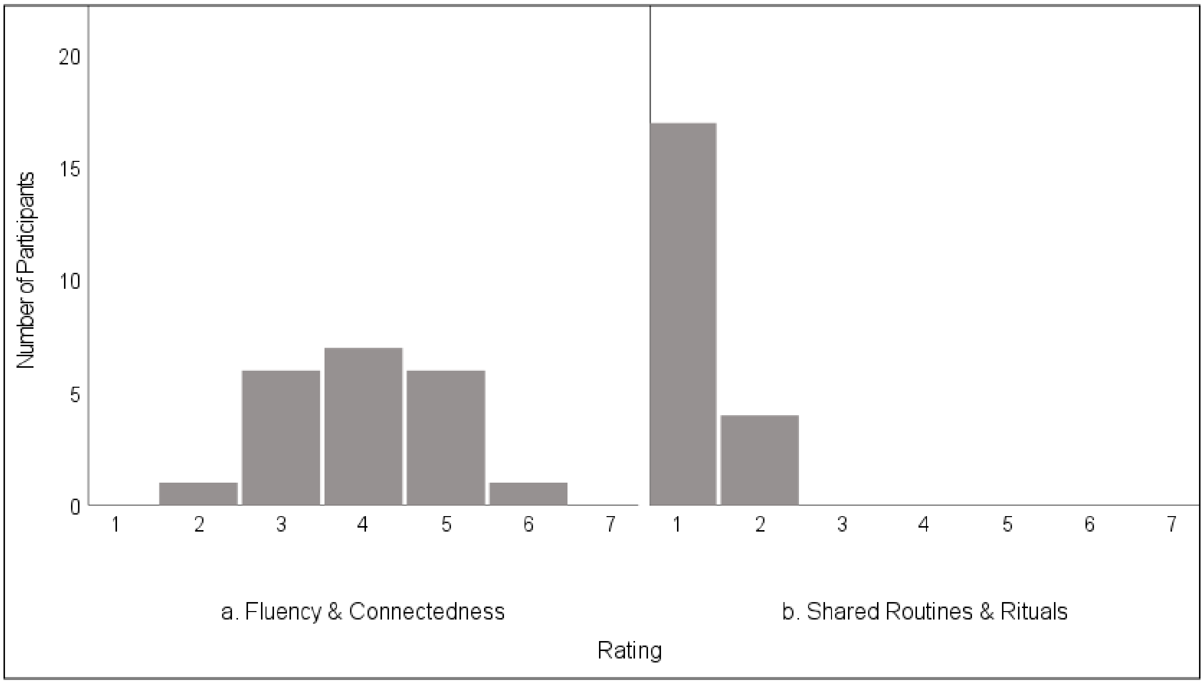

Figure 2.10. Histogram of Ratings for Dyadic Interaction Items (N=21).

2.4.5. Changes Between Parent-Child Interaction (PCI) Parts I and II

As outlined in the methodology, the PCI-recorded interaction videos consisted of two parts. In Part I, the caregiver was seated while the child explored the room and available toys. In Part II, the child and caregiver were actively engaged. Only four items were rated in both Part I and Part II of the PCI, including unengaged, object engagement, child's expressive language level and use, and child's attention to caregiver. A comparison of the ratings for unengaged in Parts I and II is shown in Figure 2.11. The ratings for unengaged remained low across PCI Parts I and II, indicating that children were almost constantly engaged (in objects and events and/or with the caregiver) in both parts of the PCI. Figure 2.12 shows that most children had more extended periods of object engagement with higher quality in Part I versus Part II. When considering the differences in object engagement between Parts I and II, it is essential to note that joint engagement was only rated in Part II and not in Part I. Therefore, in Part II, the children may have spent less time in object engagement because some of the 6-minutes were accounted for in joint engagement.

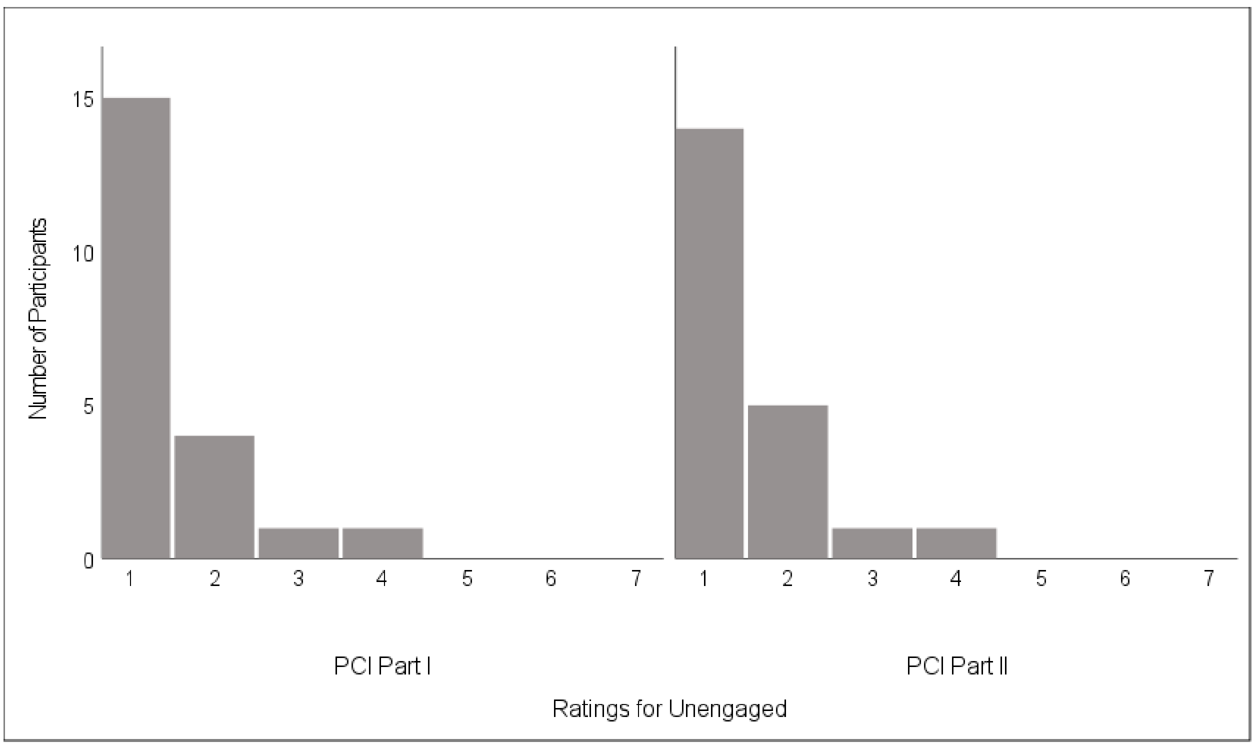

Figure 2.11. Histogram of Ratings for Unengaged: Part I vs Part II (N=21).

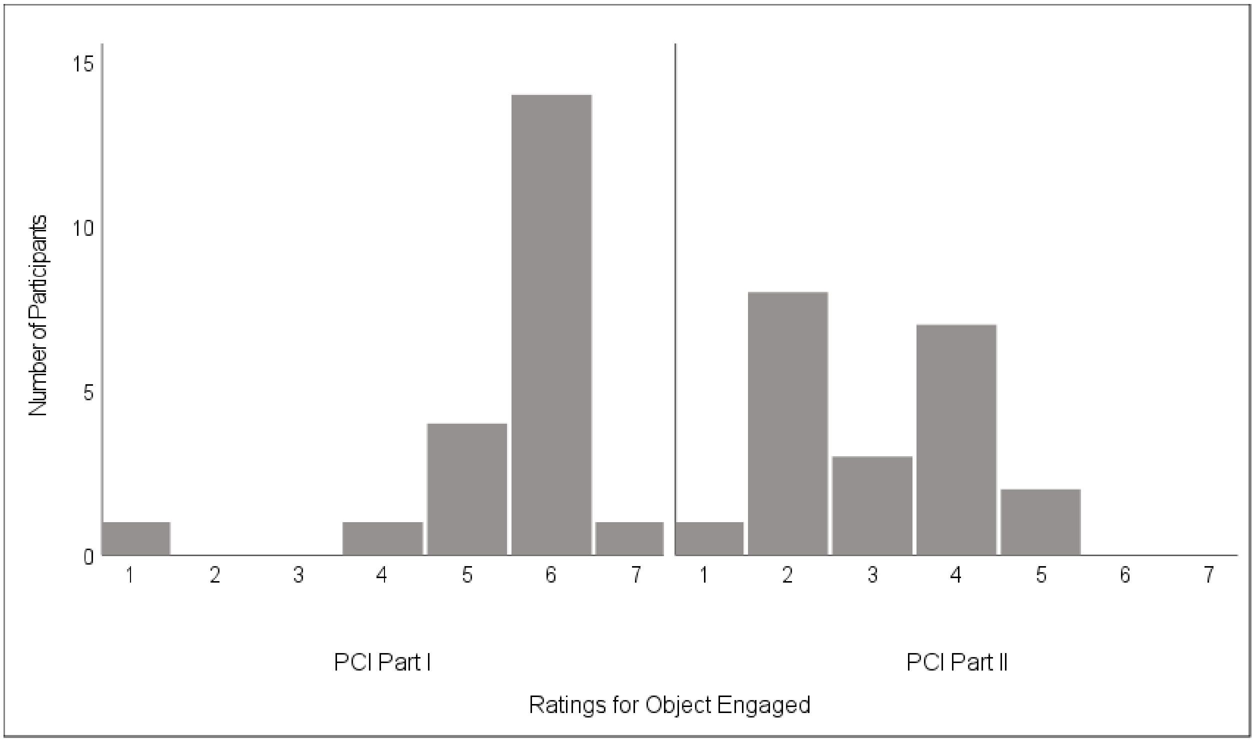

Figure 2.12. Histogram of Ratings for Object Engagement: Part I vs Part II (N=21).

The results for expressive language level and use show that although, on average most children were rated a 2 (used about 1-4 different single words) in both Parts I and II, the ratings were more spread out in Part II. Figure 2.13 shows that two more children were rated 3, and one more was rated a 5 in Part II, suggesting that more children used more expressive language in Part II. Most children paid more attention to their caregiver in Part II compared to Part I. Figure 2.14 also indicates an increase in the spread of the ratings for child's attention to caregiver between PCI Parts I and II. These changes show that more children received higher ratings for attention to caregiver in Part II. The differences in ratings for attention to caregiver are shown in Figure 2.14.

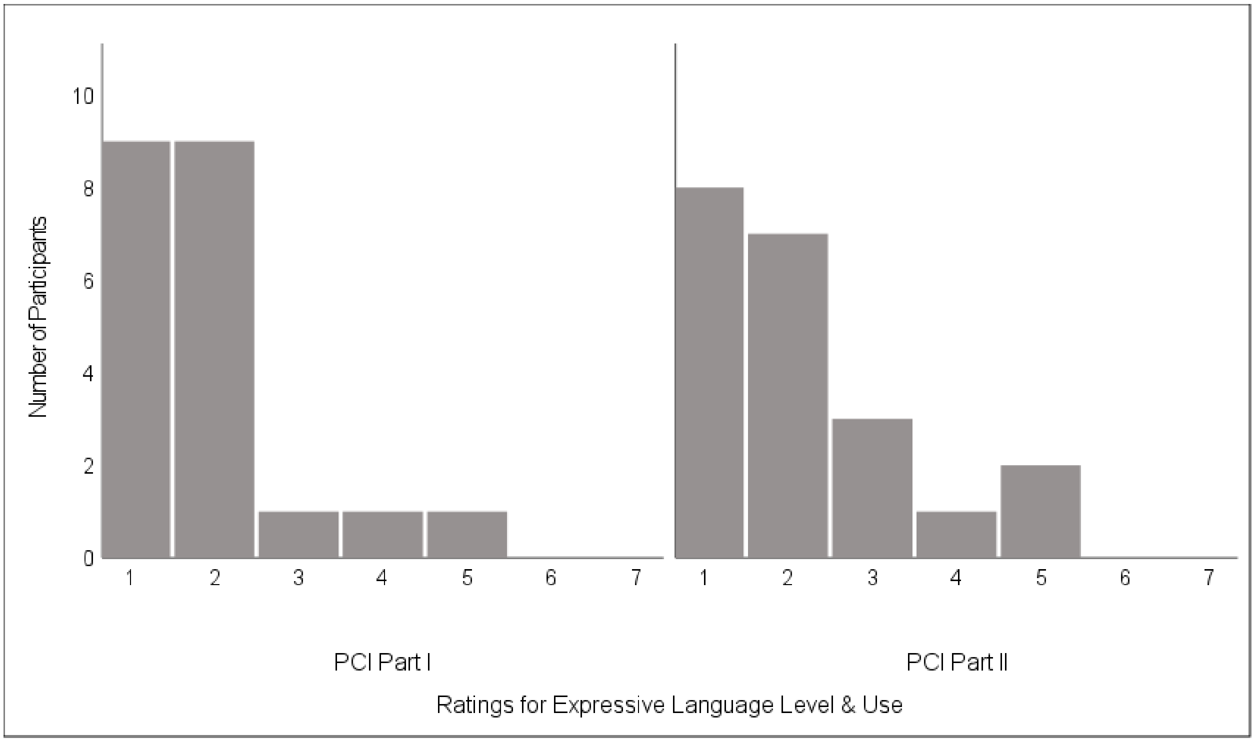

Figure 2.13. Histogram of Ratings for Expressive Language Level and Use: Part I vs Part II (N=21).

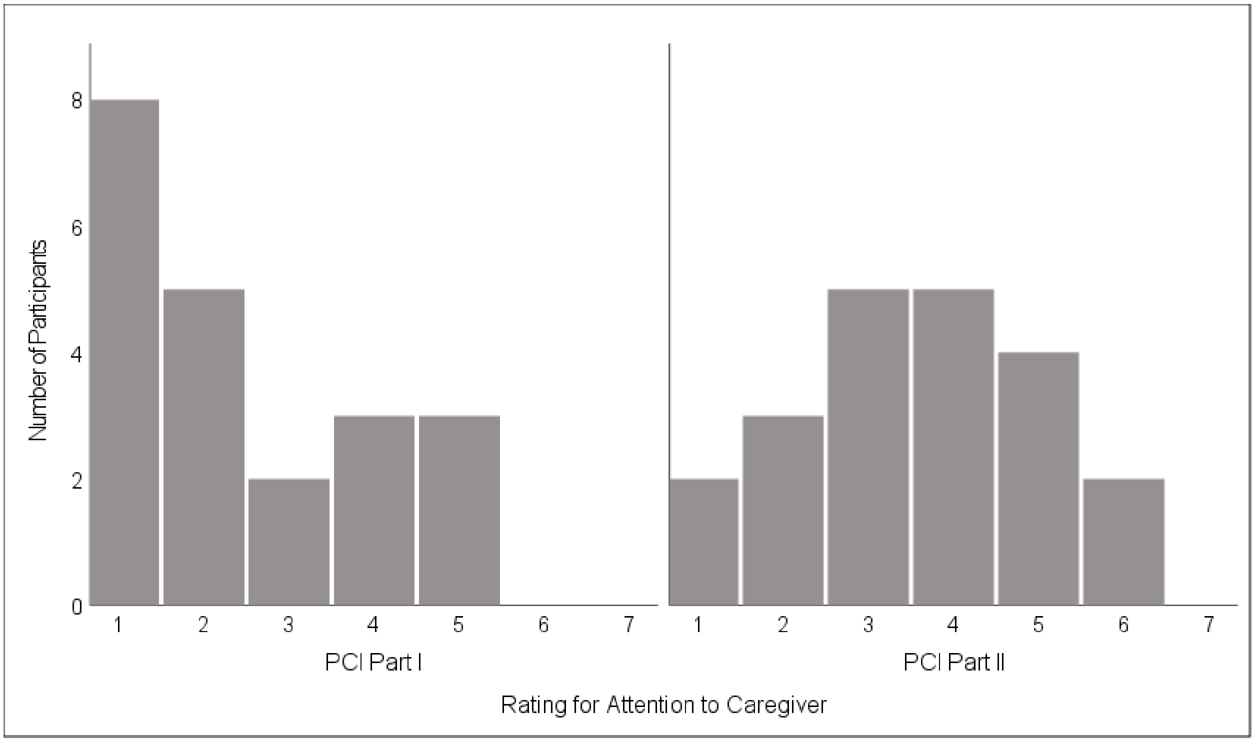

Figure 2.14. Histogram of Ratings for Attention to Caregiver: Part I vs Part II (N=21).

2.5. Discussion

Quantifying the interactions between children with ASD and their caregivers living in low-resource South African environments may assist in providing a broader understanding of the nature of these interactions and the 'fit' of naturalistic developmental behavioural interventions (NDBI) in LMIC contexts. The purpose of this study was to 1) evaluate the utility of the JERI for use in Africa by examining various aspects of reliability and validity of the tool, and 2) examine JERI observations of child engagement and behaviours, caregiver behaviours and dyadic interactions of young children with ASD and their caregivers to understand the 'fit' of NDBI in LMIC. The study used the JERI to describe the behaviours of caregivers and their children with ASD during caregiver-child interactions. We predicted that after formal training in the JERI, raters would achieve reliability for all the items in the JERI identified for the purpose of this study. We also predicted that the JERI could capture nuanced behaviours in children and caregivers during caregiver-child interactions with good face validity to ASD and ASD interventions, therefore suggesting a reasonable 'fit' of the JERI for use in NDBI in the South African context.

2.5.1. Potential Use of the Joint Engagement Inventory in South Africa

We reached reliability on the JERI for the majority of the items. The raters had between 75-100% agreement within 1 scale for all the JERI items, and the weighted kappa values for 12 of 16 items showed reasonable agreement between the two raters. The reliability results suggest that the training on the JERI was successful, and that the JERI rating scale can provide a significant and relevant reliability assessment. There was a range of ratings for JERI items across Parts I and II of the PCI with reasonable distributions. The results showed no ceiling effects, but two items in PCI Part I (unengaged and child's expressive language level and use) and four in PCI Part II (unengaged, coordinated joint engagement, symbol-infused joint engagement and shared routines and rituals) showed floor effects. The distribution of ratings for the child engagement state items and the child activity items were reasonable based on existing knowledge of the developmental differences that young children with ASD may have. The child behaviours characterised by the child engagement state items and child activity items also match onto child treatment targets within NDBI. We propose that the floor effects observed in this study do not indicate that the JERI is unsuitable for use in the South African context but reflect the behavioural characteristics related to ASD in our sample of children. Additionally, the caregiver-child interaction videos were recorded in a lab-based environment with standardised materials. We propose that the dyads' possible unfamiliarity with the environment and materials used in the PCI recording may inform the low ratings for shared routines and rituals. It may not come naturally to demonstrate some clear and established routines in an unfamiliar environment with possibly unfamiliar materials.

There were changes in the range of ratings for two child activity items (expressive language level and use and attention to caregiver) between Parts I and II of the PCI. The observed changes suggest the potential of the JERI to measure a change in child behaviours and possibly caregiver behaviours. Taking together the findings on 1) the JERI's reliability, 2) the reasonable distribution of JERI ratings, and 3) the observed changes in ratings between Parts I and II of the PCI, we propose a) that the JERI may be a consistent measure that can provide a reliable and comprehensive view of child and caregiver behaviour during caregiver-child interactions, and b) that the JERI, therefore, has potential utility as an outcome measure to examine change in child behaviour, caregiver behaviour, and caregiver-child interactions affected by caregiver-mediated NDBI also in a local South African context.

2.5.1.1. Child Behaviours

The results showed no ceiling effects, but two items in PCI Part I (unengaged and child's expressive language level and use) and four items in PCI Part II (unengaged, coordinated joint engagement, symbol-infused joint engagement and shared routines and rituals) showed floor effects, with most ratings on the lower end of the scale. The floor effects suggest that children in this study seldom made explicit eye contact with their caregiver during caregiver-child joint activities. They rarely used language or gestures related to the current focus of the shared caregiver-child activity. The children in our study also used limited expressive language, speaking primarily in single words. These results are also in keeping with previous findings where the JERI was used to rate the behaviours of young children with ASD (Adamson et al., 2019; Killmeyer & Kaczmarek, 2017; Mayo et al., 2013; Suma et al., 2016). We propose that the floor effects observed in this study could be attributed to the behavioural characteristics of ASD in young children. For example, challenges in acquiring receptive and expressive language, eye contact and symbolic play skills, resulting in low JERI ratings for these child activity items. The skills and behaviours observed at low levels in our study (i.e., explicit eye contact and expressive and receptive language use) are typically targeted by NDBI approaches. These findings suggest a degree of 'fit' between children with ASD in a South African context and NDBI approaches. Additionally, we propose that the JERI can be used to measure child behaviours that are targeted by NDBI. Therefore, evaluating the utility of the JERI to measure change affected by NDBI is important to explore.

2.5.1.2. Caregiver Behaviours

As mentioned earlier, the dynamic changes observed in two child activity items (expressive language and attention to caregiver) between Parts I and II of the PCI suggests that the JERI may be used to measure change in treatment targets affected by

NDBI. We also propose that changes in child behaviours between Parts I and II of the PCI suggest that caregiver presence during child play supports expressive language use and attentional shifts in children with ASD, which further supports the potential of caregiver-implementation of NDBI in the South African context. Caregivers in South Africa can be coached to implement NDBI strategies in the context of shared interactions with their children. The caregiver’s presence (and involvement) in their child’s activities, coupled with the caregiver’s implementation of NDBI strategies, creates a significant potential for improving child outcomes. Caregiver-implemented interventions can improve child engagement and attention (Kasari et al., 2010). Child engagement and attention may subsequently promote language development in young children with ASD (Dawson et al., 2004; Schreibman et al., 2015). Increased caregiver use of NDBI strategies during caregiver-child interactions may improve child outcomes (i.e., social communication skills, language development, symbolic play skills) as well as key features of caregiver-child interactions (i.e., child’s joint engagement, caregiver behaviour and skill during shared topics, the overall flow of interactions and connectedness between dyads) (Suma et al., 2016).

The caregiver activity items assessed caregiver behaviours that may support and expand child activity, engagement, and language. The results indicated that most caregivers were rated around the midpoint of the scale across caregiver activity items (i.e., scaffolding, following in on child’s focus, caregiver affect, language facilitation and communicative temptations). Caregivers showed moderate use of behaviours that could support and expand their child’s activity, engagement and expressive language use. These behaviours, for example, the caregiver's ability to initiate and sustain an interaction with their child by following their child's interest and using positive affect and animation, could support growth in the child's social communication abilities. These skills and behaviours that are characterised by caregiver items in the JERI align with the common fidelity elements within NDBI (Frost et al., 2020). The findings in this study suggest that caregivers already use some of the strategies targeted by NDBI coaching to support their young children with ASD during interactions, demonstrating a degree of 'fit' between NDBI approaches and caregiver-child dyads in the South African context. Caregivers may benefit from coaching in NDBI strategies to increase the frequency and quality of behaviours that support their child's development during caregiver-child interactions.

The findings on child and caregiver behaviours suggest the utility of the JERI to provide nuanced analyses of child and caregiver behaviour during caregiver-child interactions. These findings also suggest a potential 'fit' between NDBI approaches and caregiver-child dyads who live in low-resource South African environments.

2.5.2. Limitations of the Study

We acknowledge several limitations of this study. Firstly, the JERI was developed in a high-income setting, and to the best of our knowledge, it has not been used for research on NDBI in LMICs. There could be an inherent cultural bias in items that relate to eye contact and language use (Harrison, 2017) that may have impacted how the dyads were rated. The JERI observations of the caregiver-child were based on western constructs, and we may have missed other more nuanced South African or local constructs during the rating process. However, this study conducted the first evaluation of the JERI in South Africa, an LMIC, and has found that the JERI indicates potential utility as a measure of behaviours of young children with ASD and their caregivers during interactions in LMICs. Secondly, the procedures followed to be successfully trained in the JERI and reach reliability required significant funding, time and effort. We acknowledge a potential limitation regarding the future use of the JERI in underserved, low-resource LMIC environments. However, there is a lack of validated tools for ASD research in Africa, and through this study, there are now two trained research reliable raters of the JERI in South Africa. This study presented an essential step in evaluating the future use of the JERI in similar LMICs, especially for early ASD intervention research. Lastly, the caregiver-child interactions were recorded in a lab-based environment using standardised material. We acknowledge that some of the materials used during interactions may be western and unfamiliar to some caregiver-child dyads. We do not know whether all the materials were culturally appropriate and the implications this may have had on the caregiver-child interactions. We did not assess the cultural appropriateness of PCI materials. Therefore, important questions remain about caregiver-child interactions with familiar materials, such as those found in the home environment. Nonetheless, this study presented a range of materials readily available in low-cost stores, and the caregiver-child dyads had some choice in the materials to use during interactions. Additionally, the materials used in the PCI were not dissimilar to those of the ADOS-2, which has been evaluated for cultural appropriateness in a low-resource South African setting (Smith et al., 2017).

2.6. Conclusion

This study described and quantified the behaviours and skills of caregivers and their young children with ASD in a low-resource South African environment using the JERI. The findings from this study provided nuanced descriptions of the child and caregiver behaviours during caregiver-child interactions, which align with the child intervention targets and common fidelity elements within NDBI, suggesting a degree of 'fit' between the JERI as a potential outcome measure in NDBI in a South African context. Exploring the use of the JERI as an outcome measure, which can detect caregiver-child changes in response to intervention, is an essential next step. Further work will be required in other African contexts to evaluate the potential of the JERI to quantify caregiver-child interactions using self-selected materials and potentially home-based video recordings of caregiver-child interactions.

CHAPTER 3

3.1. Naturalistic Contexts of Caregiver-Child Interactions

3.1.1. Background

As outlined in Chapter 1, young children with autism spectrum disorder (ASD) have challenges with social communication, understanding and expressing verbal and non-verbal communication (APA, 2013; Bedford et al., 2012; Shumway & Wetherby, 2009; Sullivan et al., 2007). They can, therefore, benefit from early targeted interventions such as naturalistic developmental behavioural interventions (NDBI) (Lord et al., 2021; Sandbank et al., 2020). NDBI are emerging as contemporary early interventions for addressing the core challenges associated with ASD (Lord et al., 2021; Sandbank et al., 2020). NDBI approaches are underpinned by behavioural and developmental theories of learning and development (Lord et al., 2021; Sandbank et al., 2020; Schreibman et al., 2015). They target critical foundational social, language and cognitive skills in young children with ASD (Sandbank et al., 2020; Schreibman et al., 2015). A common and essential feature of NDBI (among others) is implementing interventions in *naturalistic* environments (Schreibman et al., 2015). Caregivers can be coached to deliver NDBI to their young children with ASD during naturally-occurring daily shared routines within naturalistic environments (Schreibman et al., 2015). Daily social activities and routines provide rich learning contexts for children and implementing NDBI within these naturalistic contexts may impact child outcomes, such as the development of early social communication, language and play skills (Sandbank et al., 2020; Schreibman et al., 2015; Tiede & Walton, 2019). Therefore, it is crucial to understand the social activities children with ASD engage in and the main partners or caregivers involved in those activities. Acquiring this knowledge can guide the relevance of NDBI-informed caregiver coaching.

To date, the vast majority of developmental and behavioural research that underpins NDBI has been conducted in high-income 'western' contexts. The predominant knowledge base around NDBI is, therefore, based on the naturalistic routines of white, monolingual, English-speaking, middle-socio-economic status participants from high-income countries, with less than 3% of research participants from low/middle-income regions (Durkin et al., 2015; Fannin, 2017; Nielsen et al., 2017). There is a lack of research on the application of NDBI in culturally and linguistically diverse low-and middle-income countries (LMICs) (Lord et al., 2021), and the application of NDBI in these contexts may require adaption. The adaption of NDBI in LMICs requires an understanding of the multiple naturalistic activity settings of young children with ASD, in which we can embed NDBI. Ramseur et al. (2019) found that caregivers in South Africa regularly interacted with their young children with ASD during object-based play, sensory social routines, and family routines. The object-based play included a shared interaction between a child and caregiver conventionally using a toy or object (Ramseur et al., 2019). Sensory-social routines include shared social interactions that do not involve toys or objects and some family routines, including bathtime and mealtime (Ramseur et al., 2019). However, the questions in Ramseur and colleagues' qualitative study mainly focused on understanding object-based play and sensory social routines. Therefore, more data are needed to identify and categorise the specific family-based activities that young children with ASD in low-resource South African settings engage in and the caregivers involved. It is essential for the content of activity settings targeted within NDBI-informed caregiver coaching to align with children’s daily activities in LMICs. Identifying the multiple activities within several different activity settings (e.g., care routines, mealtimes, social play, books, toy play and chores, see Figure 3.1) of children with ASD in LMICs, will inform intervention adaptations to ensure the cultural appropriateness and ‘fit’ of NDBI in LMICs. Therefore, this study sought to describe the types of common activities that young children with ASD who live in low-resource South African environments participate in. To collect data, we selected a locally-adapted measure, The Parent Survey of Home and Family Experiences.

Figure 3.1. Child Daily Activities. Duke Centre for Autism and Brain Development & the Centre for Autism Research in Africa, University of Cape Town, 2020. Reprinted with permission.

3.1.2. The Parent Survey of Home and Family Experiences (PSHFE)

The Parent Survey of Home and Family Experiences (PSHFE) is a semi-structured interview schedule developed in the United States of America to identify child activities within the family context that represent sources of children's learning opportunities (Dunst & Bruder, 1999). Balton and colleagues then adapted the interview schedule to be used in a South African context by including contextually relevant activities for children living in South Africa (Balton et al., 2019). The adapted interview schedule consisted of closed- and open-ended questions. It was designed to interview caregivers about the types of activities their child participates in, the partners involved in the activities, the primary purpose of the activities, and the caregiver's perceptions about these activities in relation to the child's learning (Balton et al., 2019). Balton et al. (2019) used the interview schedule in their mixed-methodological study to describe the family routines of typically developing children from Soweto, one of the largest high-density 'township' communities in South Africa. The author described a wide range of activities that children participated in and identified those of higher frequency (child routine activities, play activities and spiritual activities) and of lower frequency (chores and early literacy). Importantly, they found that the level of children's participation in activities highly depended on the family's beliefs, values, practices and available resources (Balton et al., 2019). To our knowledge, the PSHFE, as adapted by Balton et al. (2019), has not been used with children with neurodevelopmental disorders, such as ASD. Children with ASD may not necessarily engage in the same types of activities as children who have typical or delayed development (Bandini et al., 2013), given their delayed/disrupted development in early social communication and language skills (Shumway & Wetherby, 2009). However, given the innovative and contextually relevant adaptions by Balton et al. (2019), we were keen to use the PSHFE in the context of ASD.

The purpose of the study was to collect data that would provide a broader understanding of the naturalistic context of common activities of children with ASD living in a low-resource South African environment in order to inform the implementation of NDBI within the daily lives of families living in an LMIC context like South Africa. We, therefore, set out to describe the typical activities of young children with ASD living in a low-resource South African context using the Parent Survey of Home and Family Experiences (PSHFE). We expected the study's findings to help us understand the naturally occurring activities of young children with ASD in South Africa and the caregivers involved to inform the relevance of caregiver-mediated NDBI in a South African context.

3.2. Methodology

3.2.1. Study Design

This study utilised a descriptive design. Semi-structured interviews with caregivers were conducted using the Parent Survey of Home and Family Experiences (PSHFE). Given that this study was conducted during the COVID-19 pandemic, all enrolment, consent and data collection had to be performed using remote procedures.

3.2.2. Research Procedures and Data Collection

3.2.2.1. Participant Recruitment and Enrolment

This study was a secondary analysis of data collected in a primary project. The recruitment and enrolment procedures described below were implemented in the primary study. Eligible families with a child with ASD within 18-72 months of age were identified by recruitment partners, Western Cape Education Department Schools. These schools had records of children with ASD (who received an ASD diagnostic assessment) waiting for public sector special education services. Families were invited to participate in the study by school staff. The project coordinator contacted those who were interested to explain the study. If the caregiver-child dyad met the criteria and the caregiver provided informed consent, the dyad was enrolled. In the case of this study, assent was not included, given that all children were younger than six years of age. As listed above, enrolment and consent processes were performed remotely.

3.2.2.2. Data Collection

Individual semi-structured interviews were conducted by the researcher (author of this dissertation) with the caregivers during a landline or mobile phone call. Before the telephonic interview, the caregivers were sent a picture of the response options for the closed-ended questions. The researcher commenced the interview by calling the caregiver, stating the purpose of the interview, and providing the caregivers time for questions. Questions were read out sequentially, and the researcher recorded the responses immediately on the interview schedule. All open-ended questions were audio-recorded and transcribed verbatim immediately after the interview was conducted. The interview was concluded by thanking the caregiver and asking whether they had questions or comments about the interview and study. Interviews took approximately 45 minutes to complete.

3.2.3. Measures

3.2.3.1. Parent Survey of Home and Family Experiences (PSHFE)

As outlined above, the Parent Survey of Home and Family Experiences is an interview schedule developed to identify activities within the family context that are a source of children’s learning opportunities. The interview schedule included both closed- and open-ended questions. Table 3.1 shows a summary of Part 1 of the survey. Fifty items (50) were rated across eight categories of activities (child routine activities, play activities, early literacy activities, entertainment activities, chores, spiritual activities, family activities, and community activities). As shown in Figure 3.2, caregivers were asked to comment on (1) the frequency of participation and reasons for non-participation in the activity, (2) the partners involved in the activity with the child, (3) the main purpose of the activity, (4) and provide a rating on a scale of 1-3 of how important the caregivers thought the activity was for learning.

Table 3.1. *Activities in Part I of the Parent Survey of Home and Family Experiences*

Category	Explanation	Activities
Child routine activities	Relate to day-to-day childcare and personal hygiene.	Family meals, bathing, brushing teeth, dressing and undressing, toileting, washing hands, haircut/style, carried on back, visiting a community clinic.
Play activities	Play activities consist of physical, constructive and symbolic activities that children enjoy and do for fun.	Playing with toys, cell phone games, playing with sand, playing with water, playing with arcade games, pretend games, riding a bike or scooter, mokuku (hide and seek), building blocks, hand or finger games, lap games, running, jumping and chasing.
Early literacy activities	These activities are related to developing skills that are the foundation of learning, such as reading, writing, and language skills.	Having a conversation, listening to stories, telling stories, reading or looking at books, colouring, drawing and painting, cutting and pasting.
Entertainment activities	These activities are related to leisure, mainly in the media and arts.	Watching TV, listening to music, dancing, singing
Chores	These activities are related to participating or assisting in household and routine tasks.	Assist in preparing meals, setting the table, cleaning the yard, washing socks and underwear, gardening

Category	Explanation	Activities
Spiritual activities	These activities are activities related to holistic wellness, religion and cultural expression.	Praying, attending funerals, attending church, attending an ancestral ceremony.
Family activities	social activities that involve engaging with family and friends.	Family gatherings, visiting family or friends in the neighbourhood, visiting family or traditional home.
Community activities	These are related to activities in the local community and outside of the home context.	Visiting shopping malls, going to the 'spaza' shop, eating out, attending weddings, attending parties, taxi ride, visiting a park

Note. Summarised from Family-based activity settings of typically developing three-to-five-year-old children in a low-income African context (p. 58) by S. Balton, 2009, University of Pretoria. Copyright 2009 by Sadna Balton

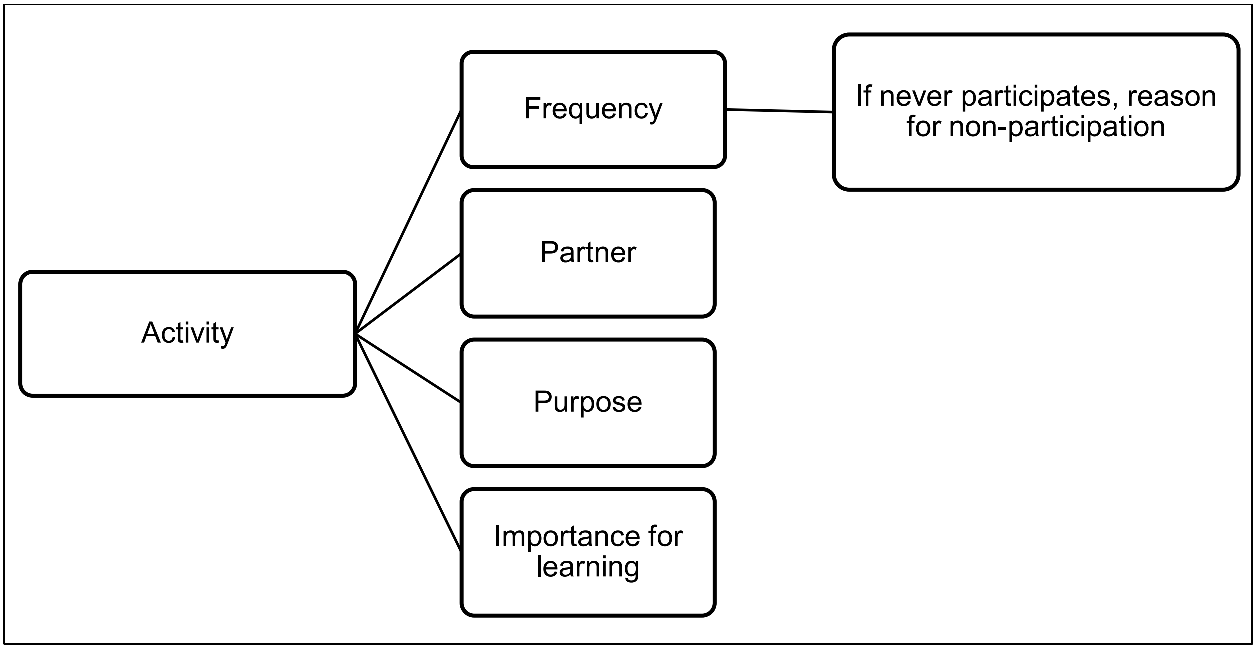

Figure 3.2. Schematic Representation of Part I of the Parent Survey of Home and Family Routines. Adapted from *Family-based activity settings of typically developing three-to-five-year-old children in a low-income African context* (p. 58) by S. Balton, 2009, University of Pretoria. Copyright 2009 by Sadna Balton.

Part II of the interview schedule consisted of four open-ended questions aimed at understanding caregiver beliefs and perceptions about their children's activities. Questions included (1) "Are there any other activities that your child does at home that you think he or she could learn from?", (2) "What do you (think) consider as the most important things for your child to learn at home?", (3) "Please list, in order of importance, 3-5 home activities that make your child laugh or smile" (interesting and enjoyable) and (4) "Please complete the following sentence: I think that my child learns best by…"

3.3. Data Analysis

The data were analysed using quantitative methods. A frequency analysis of the data from the closed questions was conducted to identify children's most frequent and least frequent activities in the study. For the open-ended questions, caregivers' responses were grouped according to common themes to identify the common perceptions among caregivers in the study.

3.4. Results

3.4.1. Participant Demographics

Interviews were conducted with a total of 10 caregivers of children with ASD living in a low-resource South Africa community in Cape Town (N = 10). The participant demographics are presented in Table 3.2. Caregivers were between 29 – 48 years of age (eight mothers; two fathers) and their children between 24 – 73 months of age (eight male; two female). All the caregiver-child dyads were Black (including Black African, Coloured and Indian). All ten children had a developmental history, and nine had an Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) (Lord et al., 2012) administered by a research reliable administrator. Six children were administered Module 1 of the ADOS-2, two the Toddler Module, and one Module 2. All children met the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), (APA, 2013) criteria for ASD.

Table 3.2 *Participant Demographics*

Participant ID	Child				Caregiver		
	Age at study entry (months)	Gender	Ethnicity/Race	ADOS-2 Module	Age (years)	Primary caregiver	Ethnicity/Race
SAESDM57	40	Female	Black African	Module1	41	Mother	Black African
SAESDM62	53	Male	Black African	Module 1	31	Father	Black African
SAESDM63	50	Male	Coloured	Toddler Module	43	Father	Coloured
SAESDM69	34	Male	Indian	Module 1	30	Mother	Indian
SAESDM70	52	Male	Coloured	Toddler Module	36	Mother	Coloured
SAESDM71	60	Male	Coloured	Module 1	31	Mother	Coloured
SAESDM72	24	Male	Coloured	Module 1	29	Mother	Coloured
SAESDM73	70	Male	Coloured	None	36	Mother	Coloured
SAESDM74	73	Female	Coloured	Module 2	48	Mother	Coloured
SAESDM76	48	Male	Coloured	Module 1	36	Mother	Coloured

3.4.2. Part I: Closed Questions

Part I of the interview schedule consisted of closed questions where caregivers were asked to comment across 50 activities on (1) the frequency of their child's participation in the activity, (2) the main partner involved in the activity with the child, (3) the main purpose of the activity, and (4) to provide a rating (on a scale of 1-3) of how important the caregivers thought the activity was for the child's learning. Below we will summarise findings across the highest and lowest participation level/frequency before presenting a summary of the open-ended question findings.

3.4.2.1. Activities with Highest Participations Levels

Figures 3.3 - 3.6 show the activities that most children (at least 50% %, N=5/10) participated in daily and the partners in these activities (grouped according to their categories). Most children participated in various activities daily across four categories (child routine activities, play activities, early literacy activities and entertainment activities). Child routine activities had the highest participation levels, followed by play, entertainment, and early literacy activities. All ten caregivers reported that their children participated in dressing and undressing daily (see Figure 3.3). Daily participation in bathing, brushing teeth, washing hands, and watching TV were reported by nine caregivers (N=10) (see Figures 3.3 and 3.4). Most caregivers reported that mothers were the main partners in the activities that most children participated in daily, followed by alone, family, parents, father, siblings, and then 'other'. Caregivers did not report grandparents and friends as the main partners in most children's activities daily.

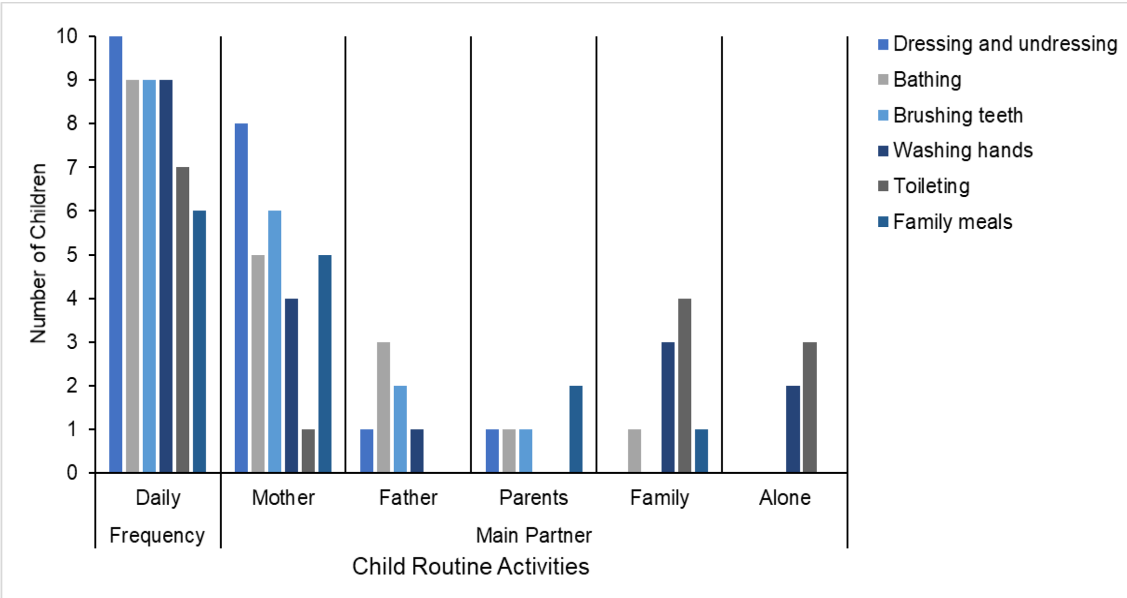

Figure 3.3 Highest Frequency Child Routine Activities & Main Partner

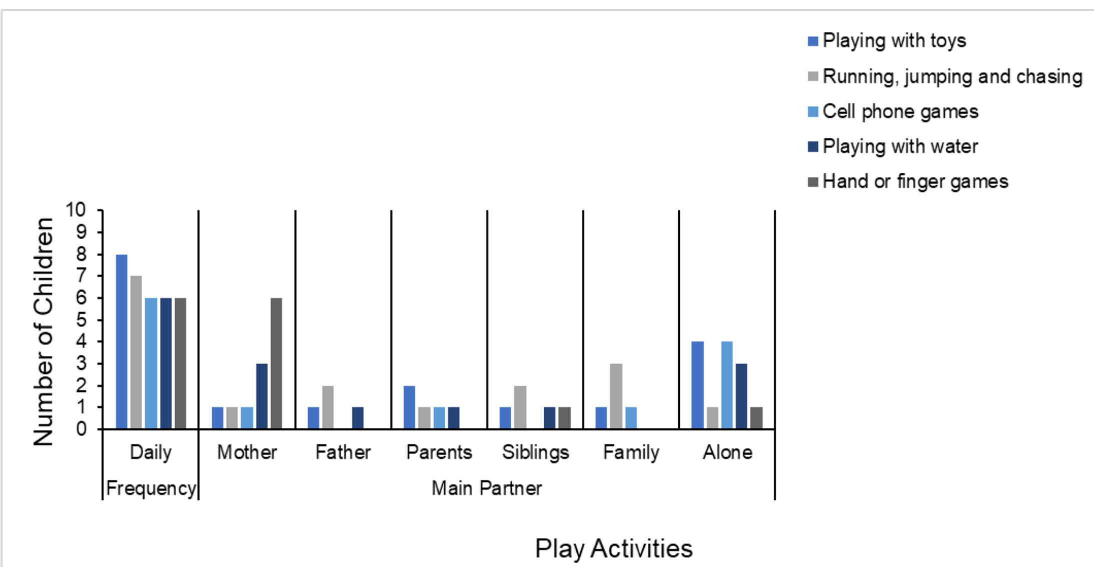

Figure 3.4. Highest Frequency Play Activities & Main Partner

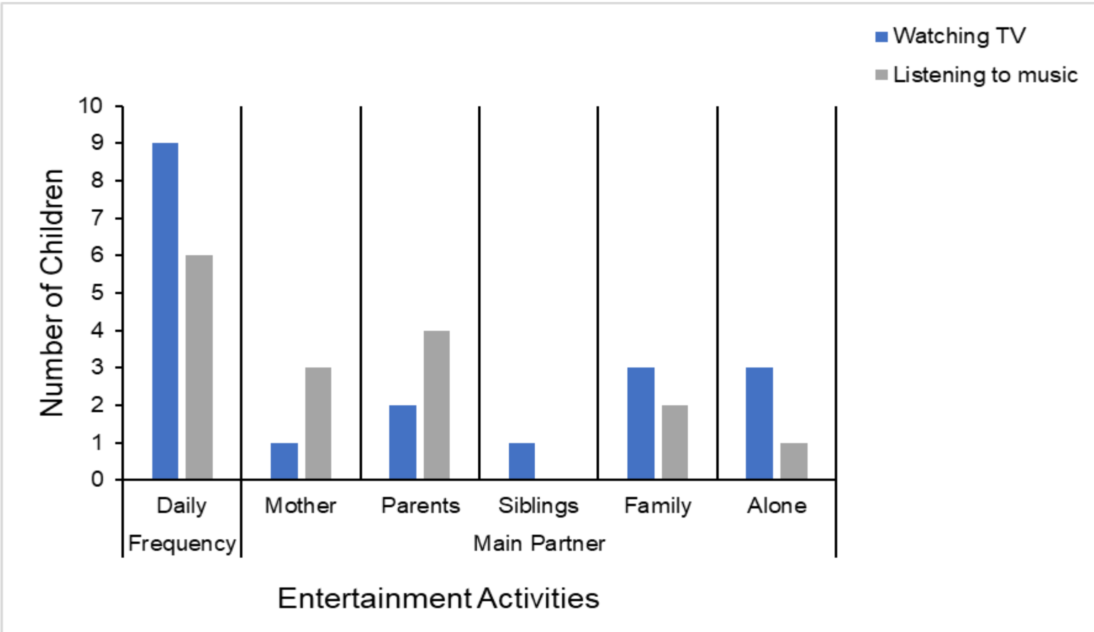

Figure 3.5. Highest Frequency Play Activities & Main Partner

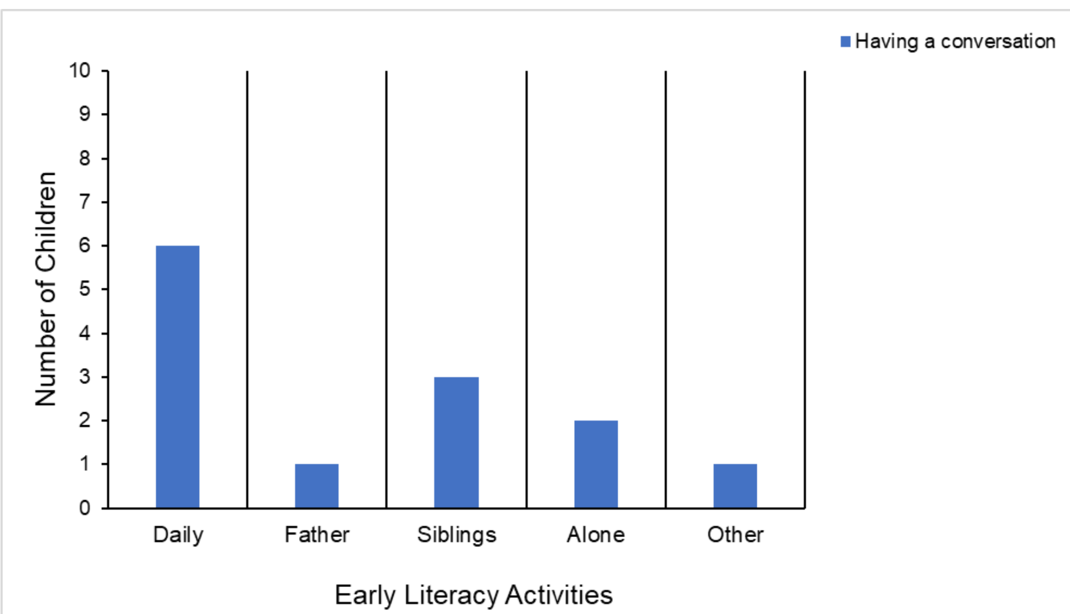

Figure 3.6. Highest Frequency Play Activities & Main Partner

Figures 3.7 - 3.10 show the most reported reasons for participation in the high-frequency daily activities and the caregiver’s rating of the activity’s importance for the child’s learning. Care was the most reported reason for participation in the activities that most children participated in daily, followed by fun, educational reasons, socialisation, other reasons, and then exercise. Caregivers did not report work, chores, or spirituality as reasons for participating in the most common daily routines. Care was the highest reported reason for participation in child routine activities. Fun was mostly reported for the play activities and entertainment activities. Most caregivers rated the activities with the highest daily participation levels as very important for the child’s learning.

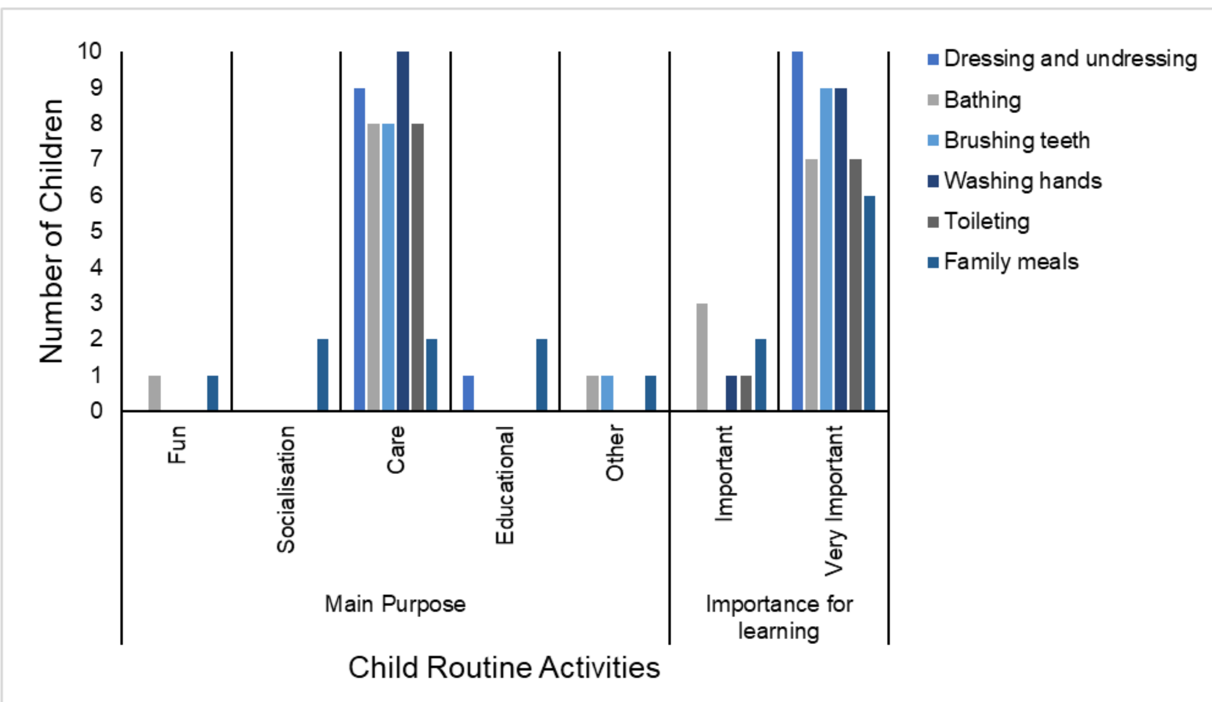

Figure 3.7. Main purpose of Activity & Importance for Learning (Child Routine Activities)

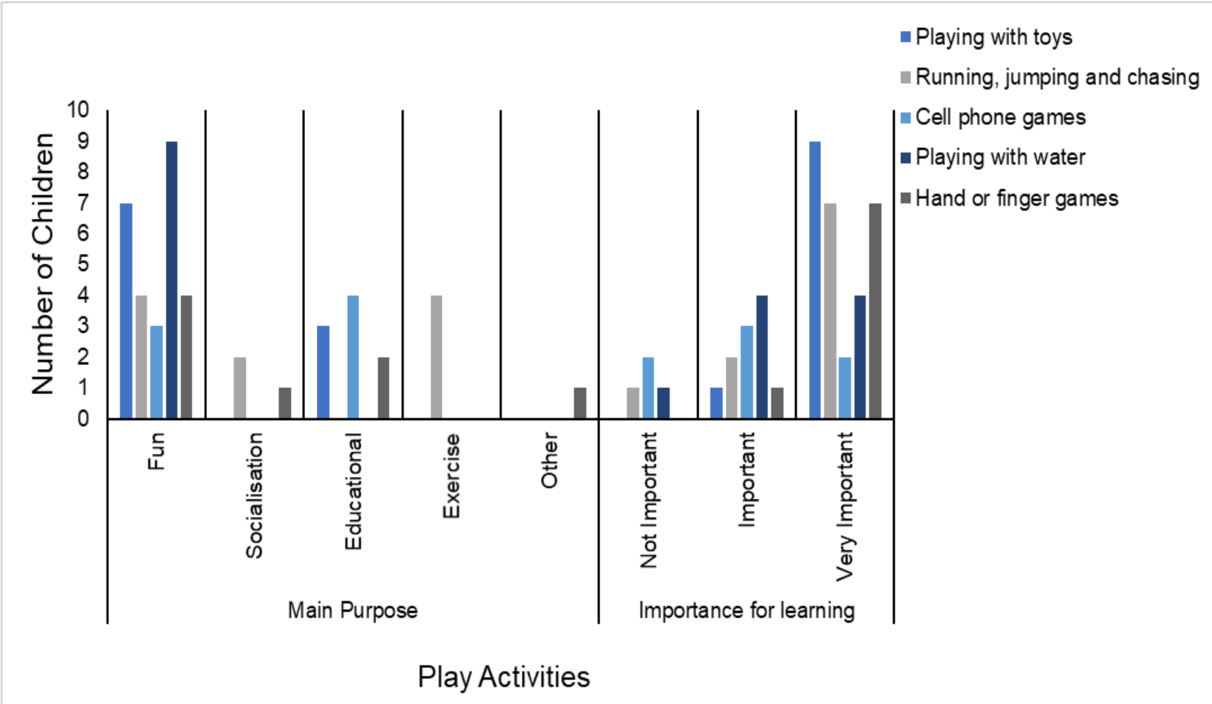

Figure 3.8. Main purpose of Activity & Importance for Learning (Play Activities)

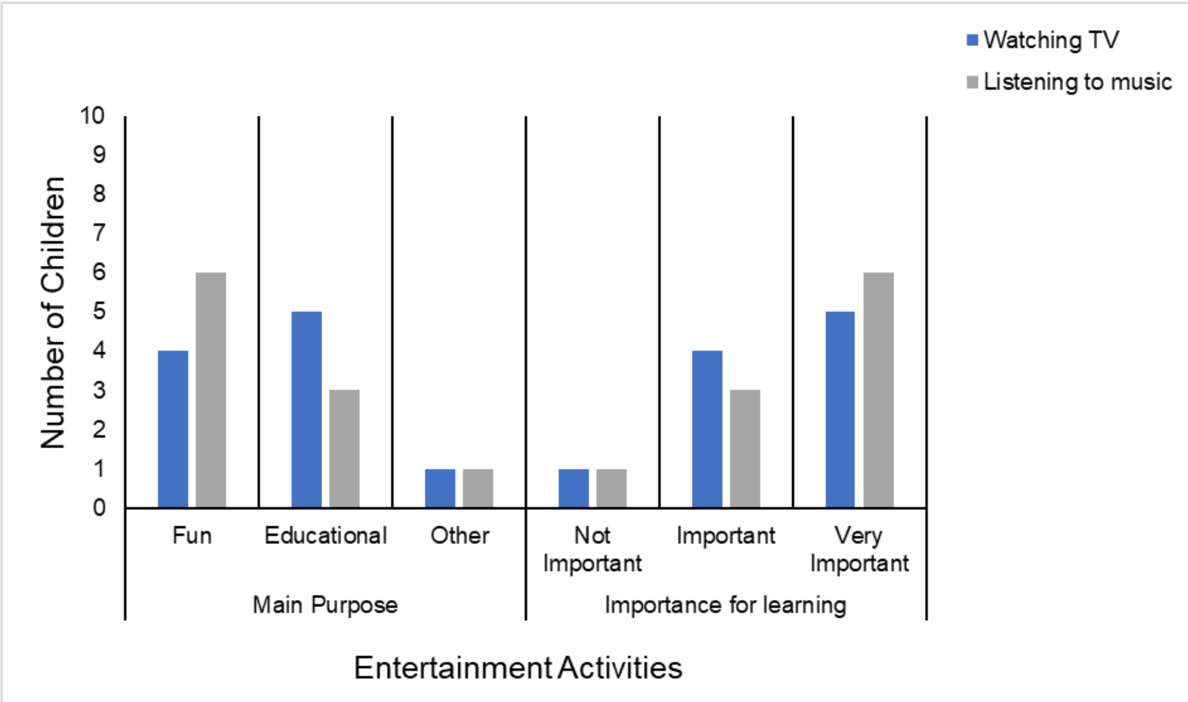

Figure 3.9. Main purpose of Activity & Importance for Learning (Entertainment Activities)

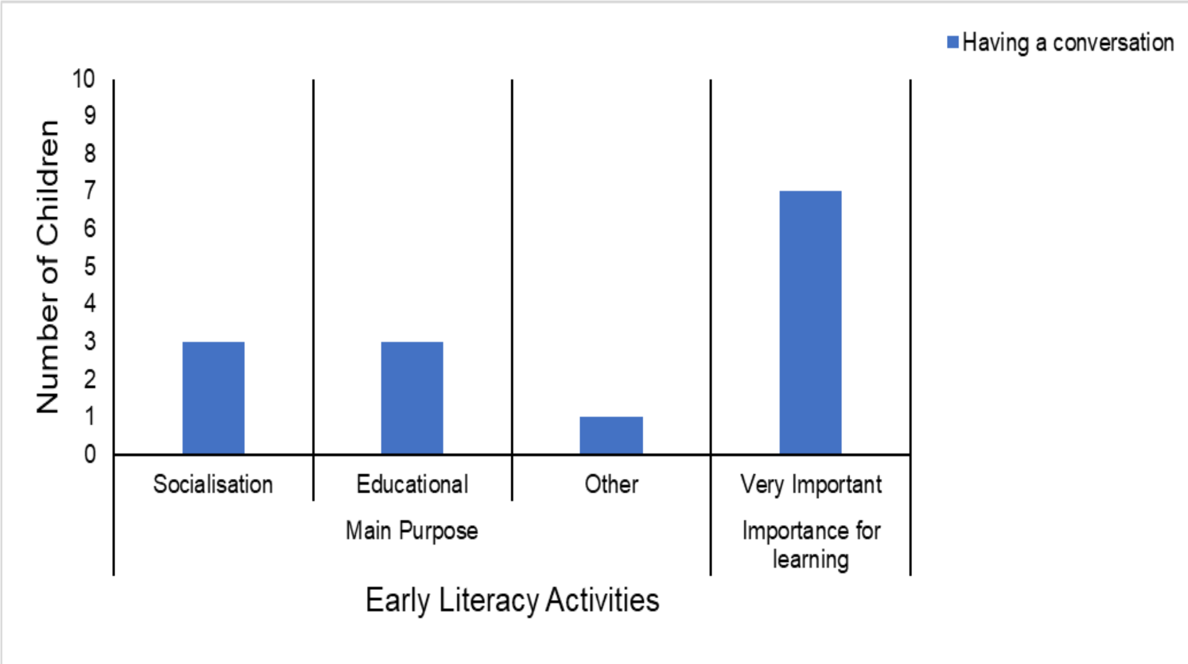

Figure 3.10. Main purpose of Activity & Importance for Learning (Early Literacy Activities)

3.4.2.2. Activities with Lowest Participation Levels

Figures 3.11 – 3.16 show the activities that most children (operationalised as 50% or 5/10) never participated in and the caregiver's reports of reasons for non-participation. The activities were grouped according to their categories. There were low participation rates for various activities in different categories, other than child routine activities, entertainment activities and family activities. Spiritual activities and community activities have the most reported activities that most children never participated in (see Figures 3.11 and 3.12). Additionally, at least six children (N=10) have never participated in any of the spiritual activities included in the interview schedule (i.e., attending an ancestral ceremony, attending church, praying, attending funerals). Attending an ancestral ceremony (a spiritual activity, see Figure 3.12) and washing socks and underwear (a chore, see Figure 3.15) had the lowest participation rates, with 90% of the caregivers (N=10) reporting that their child never participated in these two activities. Most caregivers reported that their children never participated in washing socks or underwear because of the child's age (Figure 3.15). Most caregivers reported that their children never attended ancestral ceremonies because of other reasons not provided in the interview schedule (Figure 3.12). 'Other' was the most reported reason for a child not participating in an activity, followed by the child's age, safety and transport. For the activities that most children never participated in, money, space or time were never reported by caregivers as the main reasons for non-participation.

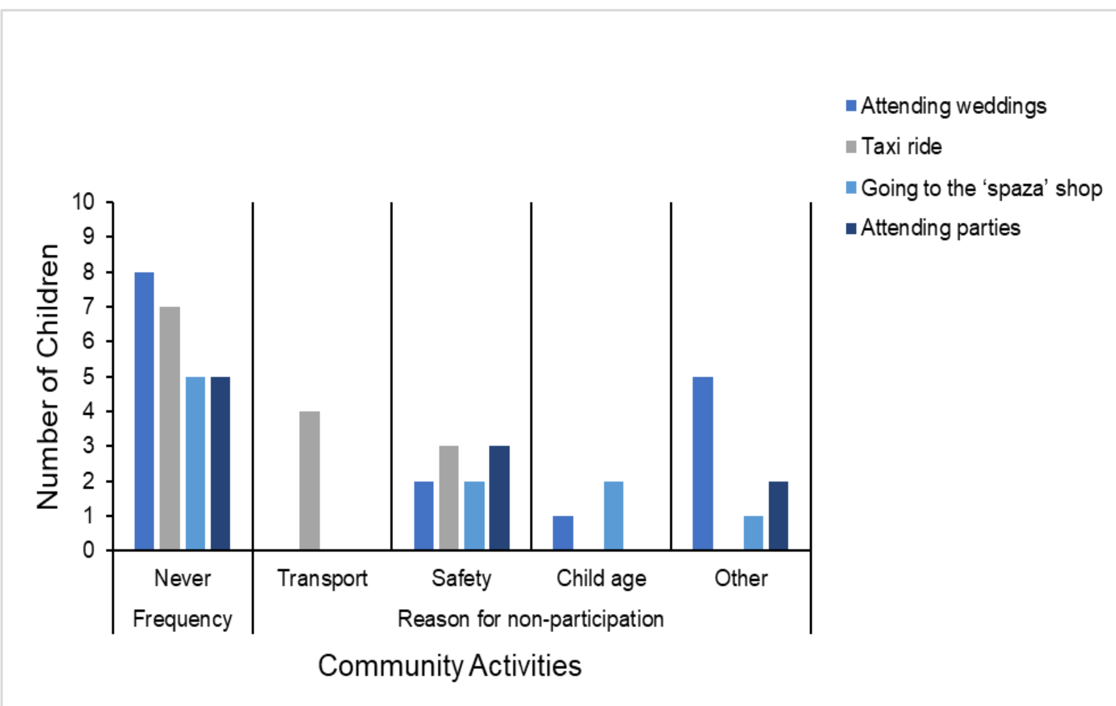

Figure 3.11. Reason for Never Participating (Community Activities)

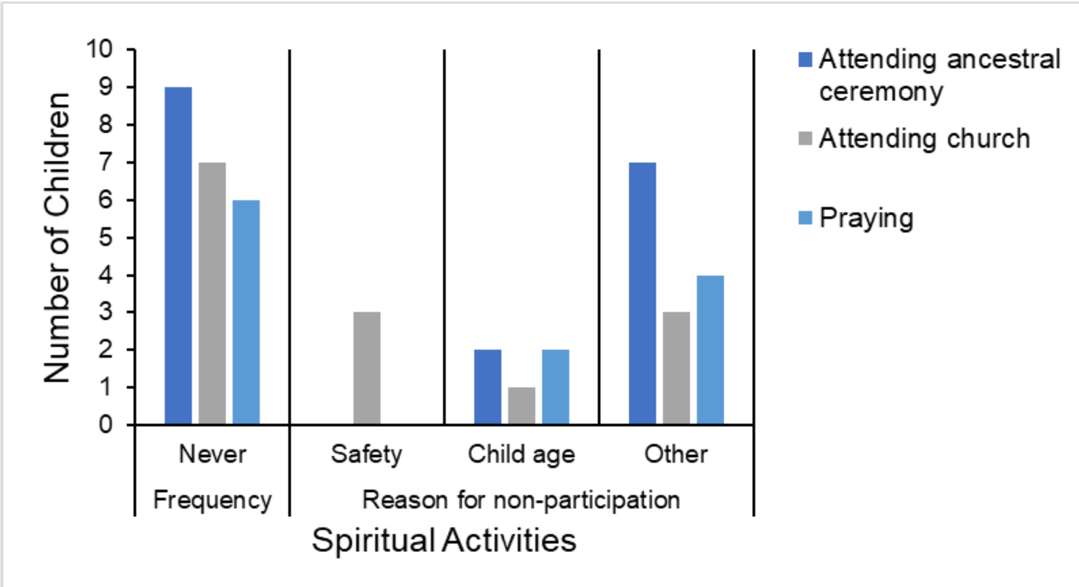

Figure 3.12. Reason for Never Participating (Spiritual Activities)

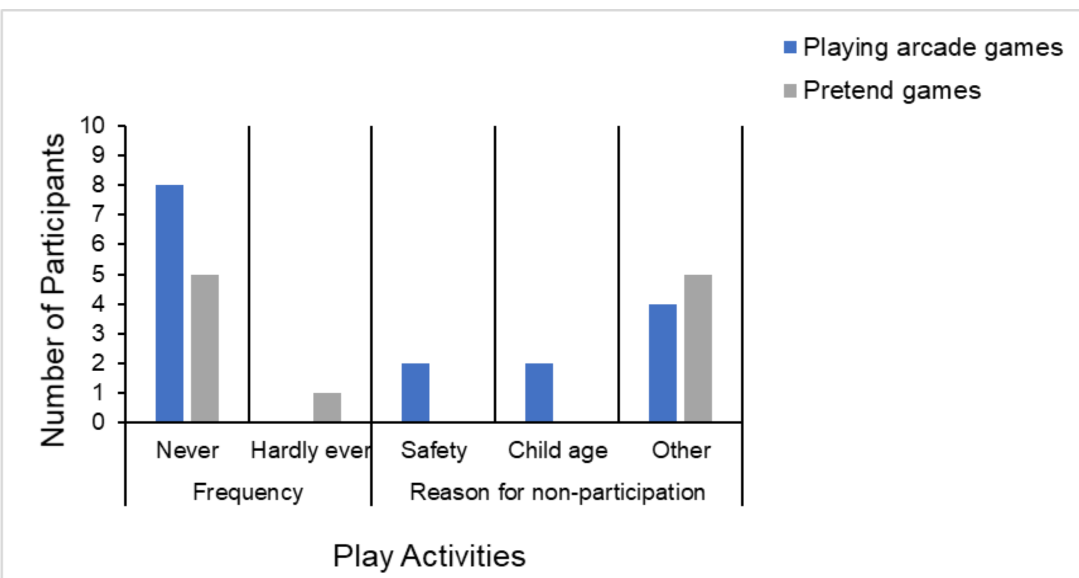

Figure 3.13. Reason for Never Participating (Play Activities)

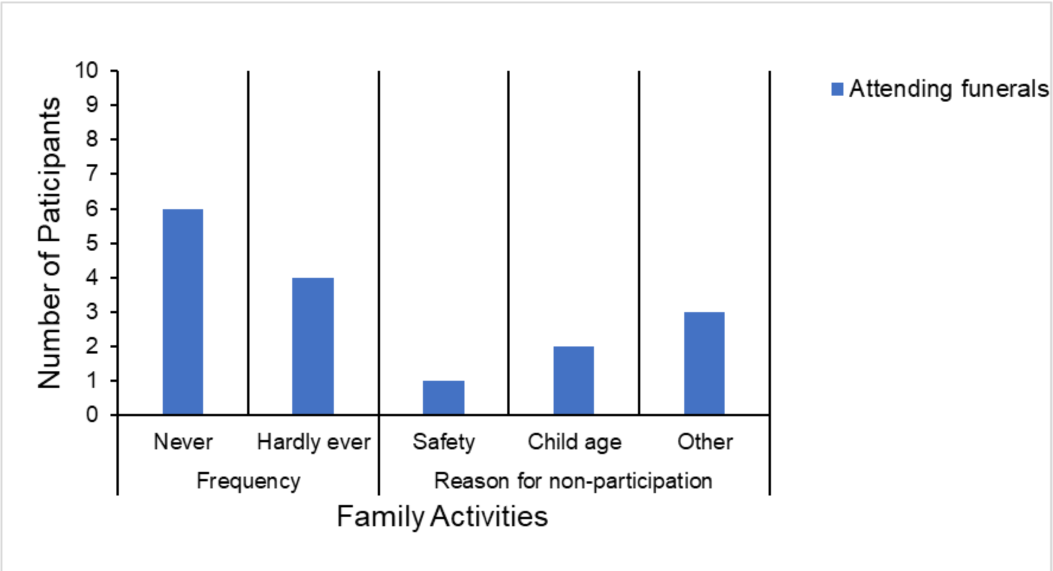

Figure 3.14. Reason for Never Participating (Family Activities)

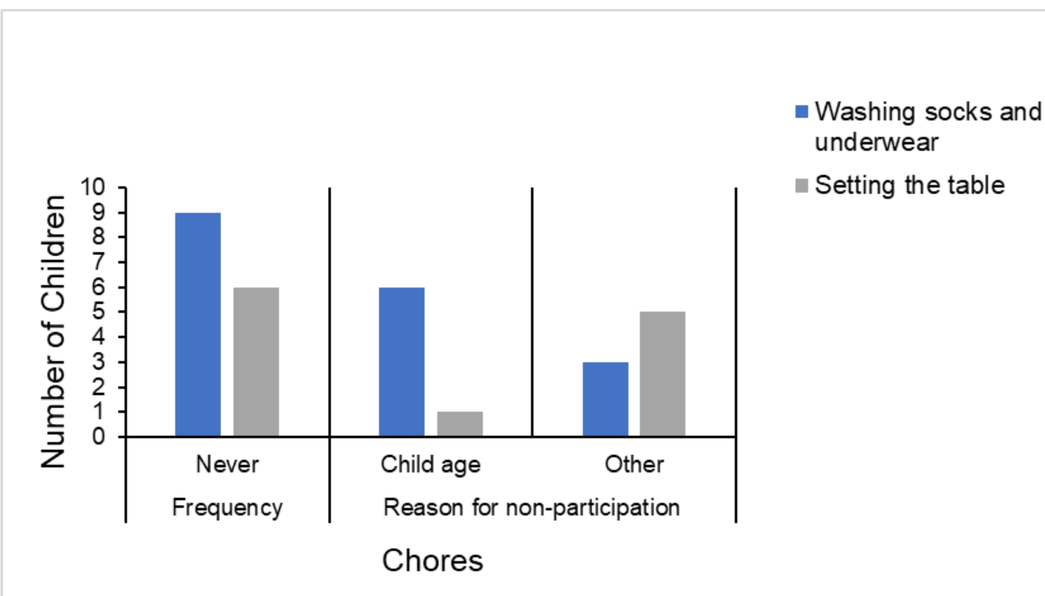

Figure 3.15. Reason for Never Participating (Chores)

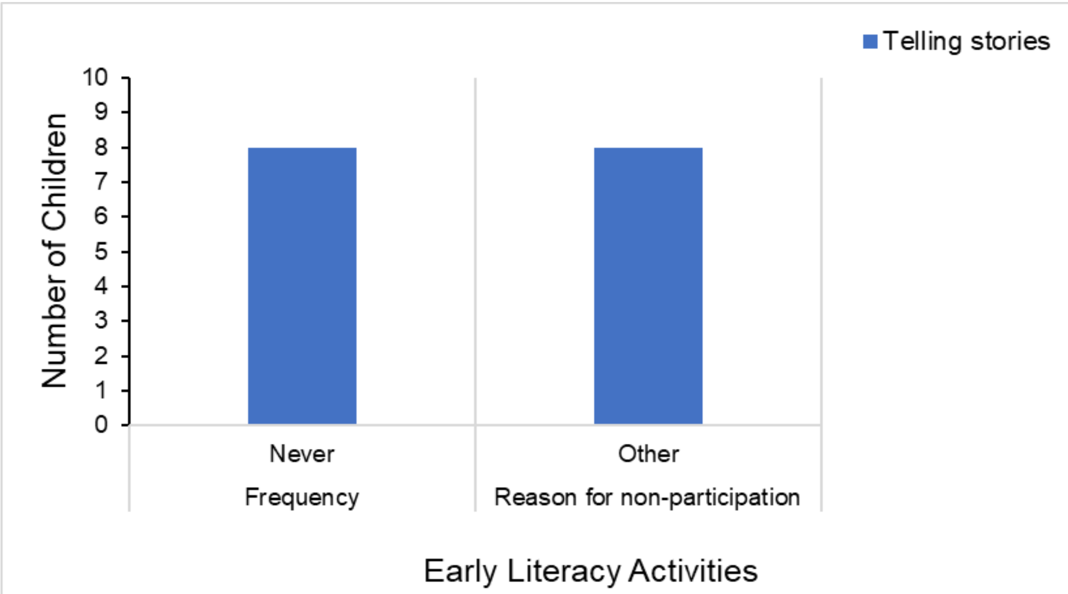

Figure 3.16. Reason for Never Participating (Early Literacy Activities)

3.4.3. Part II: Open-ended Questions

3.4.3.1. 'Are there any other activities that your child does at home that you think he or she could learn from?'

The first question sought to determine whether children participated in any other activities not included in Part I of the interview schedule. As shown in Table 3.3, four caregivers did not add any other activities. Four caregivers added various play activities, including jumping on the trampoline, swimming, building car ramps, kicking a ball and rollerblading. Two caregivers added educational/early literacy activities (flashcards, puzzles, making plastic animals) and socialising (interacting with other people, interacting with pets or animals). Only one caregiver added entertainment activities (watching YouTube videos, using a cellphone) and chores (packing clothes in the washing basket, packing groceries).

Table 3.3. *'Are there any other activities that your child does at home that you think he or she could learn from?'*

Category	Frequency (N=10)
None	4
Play Activities	4
Educational/Early literacy	2
Socialising	2
Entertainment Activities	1
Chores	1

3.4.3.2. What do you (think) consider as the most important things for your child to learn at home?'

For the second question, caregivers were asked to state what they thought were the most important things their child could learn at home. This question helped identify the different types of activities and experiences young children with ASD may be exposed to depending on their caregivers' beliefs about the importance and value of those activities and experiences. As shown in Table 3.4, self-care and hygiene (i.e., bathing, brushing teeth, self-feeding, toileting, self-dressing and having a sleep routine) and socialising (i.e., interacting with other people outside of immediate family, sitting with family during mealtimes, going to the cinema) were reported by five caregivers (50%) as the most important things for their children to learn at home. Four caregivers reported communication, specifically for their children to learn to use verbal (talking) and non-verbal (using gestures) communication to express their needs. Lastly, one caregiver stated that chores were important for their child to learn at home.

Table 3.4. *'What do you (think) consider as the most important things for your child to learn at home?'*

Category	Frequency (N=10)
Self-care and hygiene	5
Socialising	5
Communication	4
Chores	1

3.4.3.3. 'Please list, in order of importance, 3-5 home activities that make your child laugh or smile (interesting and enjoyable).'

In the third question, caregivers were asked to list three to five activities, in the order of importance, that their child enjoyed and made them laugh or smile. Table 3.5 shows that all caregivers reported that play activities, such as running, playing cell phone games, peek-a-boo, tickling, hide and seek and jumping on the trampoline, made their child laugh or smile. Nine caregivers reported that entertainment activities such as watching TV, dancing, singing, listening to music, and YouTube videos, made their child laugh or smile. Five caregivers identified self-care activities (i.e., mealtimes and bath time) as activities their child enjoyed. Three caregivers reported educational/early literacy activities (such as colouring, learning the alphabet and reading books) and two reported chores (i.e., washing dishes and packing things away).

Table 3.5. *'Please list, in order of importance, 3-5 home activities that make your child laugh or smile (interesting and enjoyable).'*

Category	Frequency
Playing	10
Entertainment	9
Self-care activities	5
Educational/Early Literacy	3
Chores	2

3.4.3.4. 'Please complete the following sentence: I think that my child learns best by…'

This question sought to determine caregivers' perceptions or beliefs about how their children learn. Caregivers identified different ways in which they thought their children learn. Table 3.6 shows that three caregivers stated that their children learn best through observation. Other caregivers mentioned that their children learn best by playing (n=2), doing and repeating (n=2), communication (n=1), interacting with others (n=1) and having fun (n=1).

Table 3.6. *"Please complete the following sentence: I think that my child learns best by…"*

Category	Frequency
Observation	3
Playing	2
Doing and repeating	2
Communication	1
Interacting with others	1
Having fun	1

3.5. Discussion

The purpose of this study was to describe the common daily routines of young children with ASD who live in low-resource South African environments. The study used a caregiver interview schedule, the Parent Survey of Home and Family Experiences, to identify the types of activities children participated in, the main partners involved in these activities, and their caregivers' perceptions and beliefs about these activities. We hoped that the results would help us understand the naturally occurring activities of young children with ASD in South Africa and the caregivers involved to inform the relevance of caregiver-mediated NDBI in a South African context.

Results from Part I of the PSHFE showed that children engaged in various activities at varying frequencies across all eight categories. Most children participated in various child routine activities, play activities, early literacy activities and entertainment activities daily. Due to their nature of being essential activities for daily care, it was no surprise that child routines (specifically, dressing and undressing, bathing, brushing teeth and washing hands) had the highest daily participation levels among most children. Most children needed assistance from mostly their mothers, fathers or sometimes both parents and family to engage in child routines. The daily occurrence of the child routine activities with their caregivers creates a context that provides child learning opportunities. Results also showed that mothers (followed by fathers) were the main partners in child routine activities. We propose that NDBI strategies can be embedded within child routines, such as dressing and undressing, bathing, brushing teeth, washing hands, toileting and family meals. These are the naturally occurring activities in which caregivers already regularly interact with their children with ASD.

Results also showed that most children never participated in most spiritual and community activities. Most caregivers reported that their children did not participate in spiritual and community activities for safety reasons. The caregiver interviews in this study were conducted during the COVID-19 pandemic, during which public participation and engagement were limited. It is important to note that the community activities and most spiritual activities in the interview schedule involve engagement in the local community and outside of the home context (i.e., community activities: visiting shopping malls, going to the ‘spaza’ shop, eating out, attending weddings, attending parties, taxi ride, visiting a park. Spiritual activities: attending funerals, attending church, attending an ancestral ceremony). Therefore, we proposed that the safety reasons (and possibly the reasons recorded as ‘other’) reported by caregivers for lack of engagement in spiritual and community activities were in relation to COVID-19 safety measures (e.g., social distancing by staying at home and avoiding crowded areas). Caregivers also mostly reported their child’s age as reasons for non-participation in the various spiritual activities (i.e., attending an ancestral ceremony, attending church and praying). We propose that the lack of engagement in spiritual activities may be attributed to children being young, as the children in this study were between 24-73 months of age. In addition to the young age, the communication and co-occurring behavioural challenges associated with ASD may have resulted in the children’s difficulty with understanding abstract concepts or following specific spiritual practice rules and rituals. We suggest that impairments associated with ASD may have also impacted the children’s lack of engagement in other activities, such as pretend games and telling stories. Many caregivers reported that their children did not participate in pretend games (a play activity) and telling stories (an early literacy activity) for other reasons. We propose that the low participation levels in these two activities may have been impacted by the behavioural characteristics of ASD in the children. Children with ASD show challenges with imaginary or pretend play and do not engage in the activity as frequently or spontaneously as their typically developing peers (Wolfberg et al., 2012). Children with ASD have also been reported to have imaginative difficulties in storytelling (Ferretti et al., 2018).

Most caregivers reported that their children watched TV for educational reasons and that it was very important or important for their child’s learning. Watching TV also had the highest daily participation rate following child routine activities. The area of learning that watching TV may support learning in children is unclear or well understood. Watching TV has previously been indicated to support the development of expressive language acquisition in some children with ASD (Fridberg et al., 2021; Kissine et al., 2019). In a study by Stiller et al. (2019), several caregivers reported that their children imitated sounds from TV. Watching TV is a norm in the daily lives of children with ASD and without ASD (Stiller et al., 2019). Screen time among children with ASD has also been reported to have increased during the COVID-19 lockdown (the period during which this study was conducted) (Kaku et al., 2021). This study aimed to identify the common daily routines children with ASD participate in to embed NDBI strategies. The results suggest that watching television is an everyday activity that the young children in our study engage in. Because watching television is a passive, independent activity, we propose that it does not lend itself well as an interactive social context that involves interactive exchanges between the child and the caregiver (or other people), in which NDBI strategies can be used. These findings can inform the relevance of caregiver-mediated NDBI in South Africa. It would be beneficial for caregivers to receive psychoeducation through NDBI that provide the necessary information about the types of activities that support the development of skills in their children. Fortunately, our results also showed that most children participated in non-passive activities in which NDBI can be embedded. Apart from the child routine activities, children also participated in having conversations and several play activities daily (i.e., playing with toys, running, jumping and chasing, cell phone games, playing with water and hand or finger games).

Most caregivers reported that their children enjoyed play activities (such as running, playing cell phone games, peek-a-boo, tickling, hide and seek and jumping on the trampoline), entertainment activities (watching TV, dancing, singing, listening to music) and self-care activities (such as mealtimes and bath time). A common feature of NDBI is following the child's lead, interest or choice by presenting teaching opportunities in the activity that a child indicates interest in (Schreibman et al., 2015). For caregiver-mediated interventions, it is beneficial also to consider activities that children enjoy within which caregivers can present teaching opportunities. When children already enjoy particular activities, child participation may be easier to encourage and for caregivers to implement NDBI strategies.

The findings highlight a range of shared child routine, play, early literacy and entertainment activities that children in our study enjoyed and engaged in on a daily basis and the caregivers involved in those activities. These daily activities align with some of the activity settings targeted within NDBI-informed caregiver coaching (i.e., care routines, mealtimes, social play, books, toy play and chores). Therefore, the findings provide relevant contextual information about the activities in which NDBI can be embedded and the typical caregivers who could be coached to implement the NDBI to their children with ASD living in low-resource South African environments.

3.5.1. Limitations of the Study

We acknowledge that the sample size for the caregiver interviews on the PSHFE was small. The small sample size was a result of limitations on enrolment and recruitment procedures imposed by COVID-19. Therefore, the results of this study may not be readily generalisable to the broader autistic population in South Africa. The small sample size also limited our ability to compare our findings with existing data on the routines of typically developing children from Balton (2019), conducted with a significantly larger sample size. However, to our knowledge, this was the first time the PSHFE was used in the context of developmental disabilities. A second potential limitation was that data collection had to be done telephonically, also given the COVID-19 pandemic. We acknowledge that network connections may not always have been reliable, which might have disrupted the flow of an interview and possibly extending the interview length. Telephone interviews may also have prevented us from picking up some of the subtle nuances of comments, for instance, given our inability to observe body language. Thirdly, we acknowledge that the PSHFE might have felt quite long to families as a telephone interview. However, although there were many questions in Part 1 of the interview, they were short, and, as described earlier, caregivers were provided with a picture of the response options for the closed questions in advance of the interviews. Therefore, we hoped that we had mitigated against some of the disadvantages of the phone interviews.

3.6. Conclusion

Despite the limitations outlined above, this study presented the first-ever systematic investigation of common daily activities of young children with ASD living in a South African environment, into which NDBI strategies could be embedded to support child generalisation of skills. We propose that future research should replicate and extend findings in a larger and more culturally and linguistically diverse sample of ASD caregivers in South Africa.

CHAPTER 4

4.1. Conclusion

4.1.1. Goals of the thesis

ASD is a life-long neurodevelopmental condition that can be identified in early childhood and is characterised by differences in social interaction and communication and restricted and repetitive behaviours or interests (APA, 2013). As outlined in Chapter 1, young children with ASD can benefit from targeted early interventions such as naturalistic developmental behavioural interventions (NDBI) (Sandbank et al., 2020; Schreibman et al., 2015). NDBI are a group of empirically-based early intervention approaches for ASD emerging as contemporary interventions, which target various developmental domains, such as early social communication, language, play and cognitive skills (Lord et al., 2021; Sandbank et al., 2020; Schreibman et al., 2015). A common feature of NDBI is implementing interventions in naturally occurring activities within naturalistic environments (Schreibman et al., 2015). Caregivers can be trained to deliver NDBI during daily caregiver-child interactions (Sandbank et al., 2020; Schlebusch et al., 2016). Even though ~95% of children with ASD and other neurodevelopmental disabilities live in low- and middle-income countries (LMICs) (Olusanya et al., 2018), research on NDBI to date have predominantly come from high-income countries (HICs), with participants from white, western, and upper/middle-socio-economic status backgrounds (Fannin, 2017; Nielsen et al., 2017). As a result, the current NDBI research did not represent culturally and linguistically diverse populations. NDBI may require adaption to 'fit' culturally and linguistically diverse LMIC contexts. We, therefore, set out to do two things in this thesis.

First, we evaluated the utility of a specific tool, the Joint Engagement Rating Inventory (JERI) (Adamson et al., 2012), developed to collect data on behaviours that caregivers and their children with ASD display during caregiver-child interactions for data collection in a culturally and linguistically diverse South African context (Chapter 2). Second, in Chapter 3, we described the activities and routines of children with ASD living in low-resource South African environments and the main partners involved in the activities with the child, using the Parent Survey of Home and Family Experiences (PSHFE) (Balton et al., 2019).

4.1.2. Summary of findings

The results of Chapter 2 suggested a potential utility of the JERI in a South African context. First, we reported that we reached reliability on the JERI for most items and proposed that the tool could, therefore, provide quantification of behaviours in a reliable manner. We examined the floor and ceiling effects, frequency distributions, median values and inter-quartile ranges of the JERI items. The results showed no ceiling effects, but floor effects in six items across Parts I and II, and reasonable distribution of ratings. These findings suggested that the JERI could provide nuanced analyses of child and caregiver behaviour during interactions. The results also showed changes in child activity items between Parts I and II of the PCI, suggesting that there is potential utility of the JERI as an outcome measure to examine change in child behaviour, caregiver behaviour, and caregiver-child interactions affected by caregiver-mediated NDBI, also in a local South African context.

We reported findings of child and caregiver behaviour during caregiver-child interactions that were characterised using the JERI. We reported that most children in our study used little expressive language (speaking in single words), seldom made explicit eye contact with their caregiver and rarely showed symbolic play skills. We proposed that these observed child behaviours are typically targeted by NDBI approaches. The results also showed that most caregivers were rated around the midpoint of the 7-point scale on the JERI for all caregiver activity items. We proposed that caregivers demonstrated moderate use of skills and behaviours that could support their child's activity, engagement and language use during caregiver-child interactions. These caregiver skills and behaviours align with the essential common elements within NDBI. Additionally, the observed changes between Part I (caregiver was seated while child explored the room and materials) and Part II (child and caregiver were actively engaged) of the PCI suggested that caregiver presence during child play supports expressive language and attentional shifts in young children with ASD. We proposed that the findings on child and caregiver behaviour during caregiver-child interactions demonstrate a degree of 'fit' between NDBI approaches and caregiver-child dyads in the South African context. The results from the PSHFE, presented in Chapter 3, showed that children engaged in various socially engaged activities daily, including dressing and undressing, bathing, brushing teeth, washing hands (child routine activities), playing with toys, running, jumping and chasing, cell phone games, playing with water and, hand or finder games (play activities), and having conversations. Mothers and fathers were reported as the main caregivers engaged in these activities with children. We proposed that these caregivers (mothers and fathers) may therefore be the most appropriate candidates to be coached to implement NDBI strategies during the daily routine activities identified in the study.

Results also showed that most caregivers reported that their children never participated in spiritual and community activities for safety reasons. We proposed that the lack of engagement in these activities was attributable to COVID-19 and related social distancing measures, given that the study was conducted during the COVID-19 pandemic and these activities involved engagement with people outside the home context.

The results suggested that children watched TV daily, and caregivers reported that their children engaged in this activity for educational reasons. Caregivers also reported that watching TV was important/very important for their child's learning. The area of learning that watching TV may support learning in children is not clear or well understood. Given that watching television is a very passive activity, we propose that it may not lend itself to a social context that involves interactive exchanges between the child and the caregiver (or other people), in which NDBI strategies can be used.

The findings from the PSHFE highlighted the various shared activities that children engaged in daily and the caregivers involved in those activities. It was encouraging that these daily activities aligned with some of the activity settings targeted within NDBI-informed caregiver coaching (i.e., care routines, mealtimes, social play, books, toy play and chores).

Figure 4.1 graphically shows us the overall study purpose and the link between the two study aims. Overall, the findings from the JERI and PSHFE provided an understanding of the nature of caregiver-child interactions and the naturalistic contexts in which they occurred in a low-resource South African environment. Our local findings, therefore, suggested that, even in low-resource communities in South Africa, the principles of NDBI may be appropriate to implement.

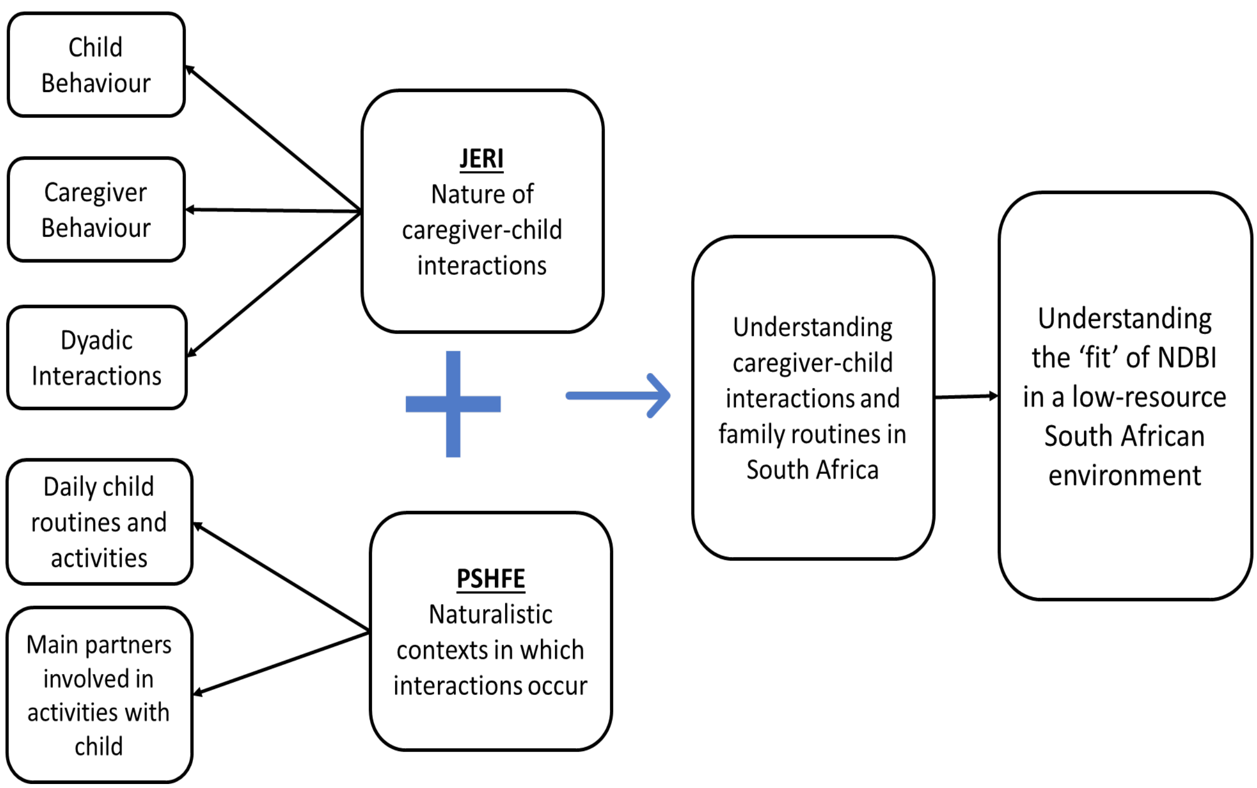

Figure 4.1 Link Diagram of the Joint Engagement Rating Inventory and the Parent Survey of Home and Family Experiences

4.1.3. Strengths and limitations of the work

This study was the first ever to use the JERI and PSHFE in the context of autism in Africa. We are therefore pleased that it contributes something to the vast knowledge gap about autism in LMICs. We hope that the small-scale studies presented in this thesis may represent a useful first step in this regard.

We acknowledged various limitations of this study in individual chapters. Given our overall goal to find truly African and afro-centric data to inform autism interventions and clinical research, it is worth acknowledging a broader potential limitation. We acknowledge that the JERI, like the majority of other autism research tools, was developed in the USA. It is, therefore, possible that high-income/western cultural biases in JERI observations of caregiver-child interactions might have been present (e.g., in what to expect and how to measure it). Linked to this, we accept that the standardised materials used in the JERI may have represented typically ‘western’ or high-income toys and play materials. Similar criticisms have been raised against the ADOS-2 (e.g., Abubakar et al., 2016). However, work in Cape Town has also shown that with minor cultural adaptations, the ADOS-2 can be a useful tool in a local context (Smith et al., 2017). The work presented here may represent a first step in this regard, and having culturally-informed raters is important to JERI implementation. We also acknowledge that training to become reliable in the JERI required significant funding, time and effort, suggesting that it would not be a tool to scale up broadly in Africa, for example. However, this was the first evaluation of the JERI in South Africa, and it has resulted in two trained research-reliable raters of the JERI in the country. We envisage tools like the JERI to be helpful in research rather than in routine clinical practice in South Africa and other LMICs.

4.1.4. Future directions

This study highlighted the need to understand the ‘fit’ of NDBI in LMICs. The JERI has the potential utility to describe caregiver-child interactions and be used as an outcome measure in LMICs. The results of the PSHFE provided contextual data of common daily activities into which NDBI strategies could be embedded to support the generalisation of skills in South Africa. In future research, the items in the JERI, especially the child and caregiver activity items, could be further adapted for specific use to reflect targeted caregiver behaviours, culturally specific nuances, and developmental expectations for children with ASD. There needs to be further research conducted in other African or LMIC contexts to evaluate the potential of the JERI to quantify caregiver-child interactions using familiar self-selected materials and quantify home-based video recordings of caregiver-child interactions. We did not identify any routines or adaptations to routines in our study that may have suggested changes to the PSHFE. However, we recommend that further research should be done to broaden the evidence-base of the PSHFE in typically developing children and in those with developmental disabilities (including autism) in the South African context. In addition, studies outside the context of the COVID-19 pandemic, which affected routines and activities in significant ways, would be invaluable.

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APPENDICES

Appendix A: Joint Engagement Rating Inventory Coding Sheet

		Anchors		
	Item	**1 =**	**4 =**	**7 =**
Child Engagement State Items	**1. Unengaged**	Almost always engaged with objects, people, and/or symbols	Unengaged for approximately a third of the scene	Almost always unengaged
	2. Object engagement	No episodes of object engagement	Spends about a third of the scene in object engagement that is of moderate quality, or briefly in object engagement in a highly striking manner	Frequently in rich and varied episodes of object engagement
	3. Child's joint engagement	No episodes of the joint engagement state	Spends about a third of the scene in joint engagement that is of moderate quality, or briefly in joint engagement in a strikingly	Frequently in rich and varied episodes of joint engagement

			high-quality manner	
	4. Child's supported joint engagement	No episodes of the supported joint engagement state	Spends about a third of the scene in supported joint engagement that is of moderate quality, or briefly in supported joint engagement in a highly striking manner	Frequently in rich and varied episodes of supported joint engagement
		Anchors		
	Items	**1=**	**4=**	**7=**
	5. Child's coordinated joint engagement	No episodes of the coordinated joint engagement state	Spends about a third of the scene in coordinated joint engagement that is of moderate quality, or briefly in coordinated joint engagement in a strikingly	Frequently in rich and varied episodes of coordinated joint engagement

			high-quality manner	
	6. Child' symbol-infused joint engagement	No episodes of the symbol-infused joint engagement state	Spends about a third of the scene in symbol-infused joint engagement that is of moderate quality, briefly in symbol-infused joint engagement in a strikingly high-quality manner	Frequently in rich and varied episodes of symbol-infused joint engagement
		Anchors		
	Items	**1=**	**4=**	**7=**
Child Activity Items	**7. Child's responsiveness to partner's communication**	Almost always resists or ignores bids	Responds to bids regularly but not continually	Responds to bids regularly but not continually
	8. Child's expressive language level and use	No expressive language	Produces many different single words during a scene with few or no word combinations	Fluent and frequent use of sentences
	9. Child's attention to caregiver	Does not pay attention to caregiver	Intermittently pays attention to caregiver	Frequently in rich and varied episodes of attending to the caregiver

Caregiver Activity Items	**10. Scaffolding**	Provides minimal support for the child's communication and/or actions on objects	Provides moderate levels of support	Continually supports and extends the child's actions
	11. Following in on child's focus	Rarely follows in on the child's current focus	Builds on the child's focus on a regular, but not continual basis	Almost continually joins and acts to sustain the child's interest
	12. Caregiver's affect	Tense, disruptive, or affectively flat, to the point of being expressionless and subsequently very hard to read	Mellow or content as opposed to flat; affect does not impede communication, but neither does it enhance it	Smoothly modulated, appropriate, and serves to enhance other modes of communication
		Anchors		
	Item	**1=**	**4=**	**7=**
	13. Language facilitation	Rare use of language facilitation strategies	Language scaffolding strategies are employed in one-third of the scene; or less time but of high quality; or more time of low quality	Continual use of a variety of language facilitation strategies

	14. Communicative temptations	Never makes any communicative temptations	Communicative temptation strategies in one-third of the scene; or less time but of high quality; or more time of low quality	Continuous flexibility in making communicative temptations
Dyadic Interaction Items	**15. Fluency and connectedness**	No interaction is established	Interaction lacks smoothness, appears to be largely dominated by one partner	Fluid and balanced interaction that is often sustained
	16. Shared routines and rituals	No evidence of routines and rituals	Some shared routines and rituals which are not sustained and do not permeate the interaction	Sustained, varied, and nuanced rituals and routines

Appendix B: Parent Survey of Home and Family Experiences

Subject ID: ______________________________

Date of Form Completion: ______________________________

No.	Activity	**Does your child participate** **in this activity?** 1 – Never 2 – Hardly ever (once a year) 3 – Sometimes (once a month) 4 – Often (once a week) 5 – Daily (every day) **If not, is it because of?** 1 – Money 2 – Transport 3 – Space 4 – Time 5 – Safety 6 – Child's age 7 – Other				**With whom does your child mainly participate with in this activity?** 1 – Mother 2 – Father 3 – Parents 4 – Siblings 5 – Family 6 – Grandparents 7 – Friends 8 – None 9 – Other		**What is the main purpose (reason) of this activity?** 1 – Fun 2 – Work or chores 3 – Socialisation 4 – Care 5 – Educational 6 – Exercise 7 – Spiritual 8 – Other		**How important do you think this activity is for your child's learning?** Please rate from 1-3 1 = Not important 2 = Important 3 = Very important	
1	Family meals	V23		V73		V123		V173		V223	
2	Bathing	V24		V74		V124		V174		V224	

3	Brushing teeth	V25		V75		V125		V175		V225	
4	Dressing and undressing	V26		V76		V126		V176		V226	
5	Toileting	V27		V77		V127		V177		V227	
6	Assist in preparing meals	V28		V78		V128		V178		V228	
7	Setting the table	V29		V79		V129		V179		V229	
8	Washing hands	V30		V80		V130		V180		V230	
9	Cleaning the yard	V31		V81		V131		V181		V231	
10	Washing socks and underwear	V32		V82		V132		V182		V232	
11	Haircut or style	V33		V83		V133		V183		V233	
12	Watching TV	V34		V84		V134		V184		V234	
13	Listening to music	V35		V85		V135		V185		V235	
14	Dancing	V36		V86		V136		V186		V236	
15	Singing	V37		V87		V137		V187		V237	
16	Praying	V38		V88		V138		V188		V238	

17	Having a conversation	V39		V89		V139		V189		V239	
18	Listening to stories	V40		V90		V140		V190		V240	
19	Telling stories	V41		V91		V141		V191		V241	
20	Reading or looking at books	V42		V92		V142		V192		V242	
21	Colouring, drawing, painting	V43		V93		V143		V193		V243	
22	Playing with toys	V44		V94		V144		V194		V244	
23	Cell phone games	V45		V95		V145		V195		V245	
24	Cutting and pasting	V46		V96		V146		V196		V246	
25	Playing with sand	V47		V97		V147		V197		V247	
26	Playing with water	V48		V98		V148		V198		V248	
27	Visiting shopping malls	V49		V99		V149		V199		V249	

28	Playing arcade games	V50		V100		V150		V200		V250	
29	Going to the ‘spaza’ shop	V51		V101		V151		V201		V251	
30	Pretend games	V52		V102		V152		V202		V252	
31	Riding a bike or scooter	V53		V103		V153		V203		V253	
32	Mokuku	V54		V104		V154		V204		V254	
33	Building blocks	V55		V105		V155		V205		V255	
34	Hand or finger games	V56		V106		V156		V206		V256	
35	Lap games	V57		V107		V157		V207		V257	
36	Carried on back	V58		V108		V158		V208		V258	
37	Running, jumping, and chasing	V59		V109		V159		V209		V259	
38	Eating out	V60		V110		V160		V210		V260	
39	Gardening	V61		V111		V161		V211		V261	
40	Family gatherings	V62		V112		V162		V212		V262	

41	Attending weddings	V63		V113		V163		V213		V263	
42	Attending parties	V64		V114		V164		V214		V264	
43	Attending funerals	V65		V115		V165		V215		V265	
44	Visiting family or friends in the neighbourhood	V66		V116		V166		V216		V266	
45	Visit family or traditional home	V67		V117		V167		V217		V267	
46	Attending church	V68		V118		V168		V218		V268	
47	Attending ancestral ceremony	V69		V119		V169		V219		V269	
48	Visiting a community clinic	V70		V120		V170		V220		V270	
49	Taxi ride	V71		V121		V171		V221		V271	
50	visiting a park	V72		V122		V172		V222		V272	

51. Are there any other activities that your child does at home that you think he or she could learn from?

52. What do you (think) consider as the most important things for your child to learn at home?

53. Please list, in order of importance, 3-5 home activities that make your child laugh or smile (interesting and enjoyable)

54. Please complete the following sentence: I think that my child learns best by

Thank you for your participation, do you have any questions or comments?

Appendix C: Parent Survey of Home and Family Experiences Summary of Findings

a. Frequency of Participation and Reason for Non-Participation

Category	Activities	Frequency					Reason for non-participation						
		Daily	Often	Sometimes	Hardly ever	Never	Money	Transport	Space	Time	Safety	Child age	Other
Child routine activities	Dressing and undressing	1-	-	-	-	-	-	-	-	-	-	-	-
	Bathing	9	-	1	-	-	-	-	-	-	-	-	-
	Brushing teeth	9	-	-	-	1	-	-	-	-	-	-	1
	Washing hands	9	1	-	-	-	-	-	-	-	-	-	-
	Toileting	7	1	-	-	2	-	-	-	-	-	-	2
	Family meals	6	1	1	-	2	-	-	-	-	-	-	2
	Carried on back	3	2	2	1	2	-	-	-	-	1	-	1
	Haircut or style	1	1	5	2	1	-	-	-	-	-	-	1
	Visiting a community clinic	-	1	2	4	3	-	-	-	-	3	-	-
Play activities	Playing with toys	8	2	-	-	-	-	-	-	-	-	-	-
	Running, jumping and chasing	7	3	-	-	-	-	-	-	-	-	-	-
	Cell phone games	6	1	-	-	3	-	-	-	-	-	-	3
	Playing with water	6	3	-	-	1	-	-	-	-	-	-	1
	Hand or finger games	6	-	1	1	2	-	-	-	-	-	-	2
	Lap games	4	2	1	1	2	-	-	-	-	-	-	2
	Pretend games	3	-	1	1	5	-	-	-	-	-	-	5
	Mokuku	3	4	1	1	1	-	-	-	-	-	-	1
	Building blocks	3	4	-	-	3	-	-	-	-	-	-	3
	Playing with sand	1	4	3	1	1	-	-	-	-	-	-	1
	Riding a bike or scooter	1	3	4	-	2	-	-	-	-	-	-	2
	Playing arcade games	-	1	1	-	8	-	-	-	-	2	2	4
Early literacy activities	Having a conversation	6	-	1	-	3	-	-	-	-	-	-	3
	Reading or looking at books	3	6	-	-	1	-	-	-	-	-	-	1
	Colouring, drawing, painting	3	3	2	-	2	-	-	-	-	-	-	2
	Listening to stories	2	2	3	-	3	-	-	-	-	-	1	2
	Telling stories	1	-	-	1	8	-	-	-	-	-	-	8
	Cutting and pasting	1	3	1	1	4	-	-	-	-	-	2	2
Entertainment activities	Watching TV	9	1	-	-	-	-	-	-	-	-	-	-
	Listening to music	6	3	1	-	-	-	-	-	-	-	-	-

Category	Activities	Frequency					Reason for non-participation						
		Daily	Often	Sometimes	Hardly ever	Never	Money	Transport	Space	Time	Safety	Child age	Other
	Singing	4	3	1	-	2	-	-	-	-	-	-	2
	Dancing	3	5	1	-	1	-	-	-	-	-	1	-
Chores	Assist in preparing meals	2	3	2	-	3	-	-	-	-	-	-	3
	Setting the table	1	2	-	1	6	-	-	-	-	-	1	5
	Cleaning the yard	1	3	1	1	4	-	-	-	-	-	-	4
	Washing socks and underwear	-	1	-	-	9	-	-	-	-	-	6	3
	Gardening	-	3	2	1	4	-	-	2	-	-	-	2
Spiritual activities	Praying	2	2	-	-	6	-	-	-	-	-	2	4
	Attending church	-	1	1	1	7	-	-	-	-	3	1	3
	Attending ancestral ceremony	-	-	-	1	9	-	-	-	-	-	2	7
Family activities	Visit family or traditional home	2	4	-	1	3	-	-	-	-	-	-	3
	Visiting family or friends in the neighbourhood	1	3	5	-	1	-	-	-	-	-	-	1
	Family gatherings	-	4	1	1	4	-	-	-	-	3	-	1
	Attending funerals	-	-	-	4	6	-	-	-	-	1	2	3
Community activities	Going to the 'spaza' shop	1	3	1	-	5	-	-	-	-	2	2	1
	Visiting a park	1	5	3	-	1	-	-	-	-	1	-	-
	Visiting shopping malls	-	3	3	-	4	-	1	-	-	2	-	1
	Eating out	-	-	4	3	3	-	-	-	-	2	-	1
	Attending weddings	-	-	-	2	8	-	-	-	-	2	1	5
	Attending parties	-	1	3	1	5	-	-	-	-	3	-	2
	Taxi ride	-	1	1	1	7	-	4	-	-	3	-	-

b. Main Partner Engaged in Activity with Child

Category	Activities	Main Partner								
		Mother	Father	Parents	Siblings	Family	Grandparents	Friends	None	Other
Child routine activities	Dressing and undressing	8	1	1	-	-	-	-	-	-
	Bathing	5	3	1	-	1	-	-	-	-
	Brushing teeth	6	2	1	-	-	-	-	-	-
	Washing hands	4	1	-	-	3	-	-	2	-
	Toileting	1	-	-	-	4	-	-	3	-
	Family meals	5	-	2	-	1	-	-	-	-
	Carried on back	3	2	2	-	1	-	-	-	-
	Haircut or style	7	1	1	-	-	-	-	-	-
	Visiting a community clinic	4	-	3	-	-	-	-	-	-
Play activities	Playing with toys	1	1	2	1	1	-	-	4	-
	Running, jumping and chasing	1	2	1	2	3	-	-	1	-
	Cell phone games	1	-	1	-	1	-	-	4	-
	Playing with water	3	1	1	1	-	-	-	3	-
	Hand or finger games	6	-	-	1	-	-	-	1	-
	Lap games	2	2	2	1	1	-	-	-	-
	Pretend games	2	-	1	-	-	-	-	2	-
	Mokuku	1	1	3	2	2	-	-	-	-
	Building blocks	2	1	1	-	2	-	-	-	1
	Playing with sand	2	1	2	1	1	-	1	1	-
	Riding a bike or scooter	1	3	1	2	-	-	-	1	-
	Playing arcade games	1	-	1	-	-	-	-	-	-
Early literacy activities	Having a conversation	1	-	3	-	2	-	-	-	1
	Reading or looking at books	3	2	2	-	-	-	-	1	1
	Colouring, drawing, painting	1	2	-	-	2	-	-	1	2
	Listening to stories	5	1	1	-	-	-	-	-	-
	Telling stories	1	-	1	-	-	-	-	-	-
	Cutting and pasting	2	1	-	-	1	-	-	-	2
Entertainment activities	Watching TV	1	-	2	1	3	-	-	3	-
	Listening to music	3	-	4	-	2	-	-	1	-
	Singing	1	-	3	1	-	-	-	3	-
	Dancing	2	-	4	-	2	-	-	1	-

Category	Activities	Main Partner								
		Mother	Father	Parents	Siblings	Family	Grandparents	Friends	None	Other
Chores	Assist in preparing meals	5	1	-	-	1	-	-	-	-
	Setting the table	2	-	-	-	1	-	-	1	-
	Cleaning the yard	1	3	1	-	1	-	-	-	-
	Washing socks and underwear	1	-	-	-	-	-	-	-	-
	Gardening	2	3	-	-	1	-	-	-	-
Spiritual activities	Praying	1	-	2	-	1	-	-	-	-
	Attending church	-	-	2	-	1	-	-	-	-
	Attending ancestral ceremony	-	-	1	-	-	-	-	-	-
Family activities	Visit family or traditional home	-	2	1	-	3	1	-	-	-
	Visiting family or friends in the neighbourhood	3	1	2	-	3	-	-	-	-
	Family gatherings	1	-	2	-	3	-	-	-	-
	Attending funerals	2	-	1	-	1	-	-	-	-
Community activities	Going to the 'spaza' shop	2	2	1	-	-	-	-	-	-
	Visiting a park	3	2	1	-	3	-	-	-	-
	Visiting shopping malls	3	-	2	-	1	-	-	-	-
	Eating out	2	-	2	-	3	-	-	-	-
	Attending weddings	-	-	2	-	-	-	-	-	-
	Attending parties	3	-	-	-	1	-	-	-	1
	Taxi ride	3	-	-	-	-	-	-	-	-

c. Main Purpose and Importance for Learning

Category	Activities	Main Purpose								Importance for learning		
		Fun	Work or chores	Socialisation	Care	Educational	Exercise	Spiritual	Other	Not Important	Important	Very Important
Child routine activities	Dressing and undressing	-	-	-	9	1	-	-	-	-	-	1-
	Bathing	1	-	-	8	-	-	-	1	-	3	7
	Brushing teeth	-	-	-	8	-	-	-	1	-	-	9
	Washing hands	-	-	-	1-	-	-	-	-	-	1	9
	Toileting	-	-	-	8	-	-	-	-	-	1	7
	Family meals	1	-	2	2	2	-	-	1	-	2	6
	Carried on back	4	-	1	1	-	-	-	2	3	2	2
	Haircut or style	-	-	-	7	-	-	-	2	1	3	5
	Visiting a community clinic	-	-	-	6	-	-	-	1	-	1	6
Play activities	Playing with toys	7	-	-	-	3	-	-	-	-	1	9
	Running, jumping and chasing	4	-	2	-	-	4	-	-	1	2	7
	Cell phone games	3	-	-	-	4	-	-	-	2	3	2
	Playing with water	9	-	-	-	-	-	-	-	1	4	4
	Hand or finger games	4	-	1	-	2	-	-	1	-	1	7
	Lap games	6	-	-	1	-	1	-	-	-	5	3
	Pretend games	4	-	-	-	-	-	-	1	-	2	3
	Mokuku	4	-	2	-	3	-	-	-	-	2	7
	Building blocks	2	-	-	-	5	-	-	-	-	-	7
	Playing with sand	8	-	-	-	-	-	-	1	3	3	3
	Riding a bike or scooter	5	-	-	-	-	3	-	-	-	3	5
	Playing arcade games	-	-	2	-	-	-	-	-	1	-	1
Early literacy activities	Having a conversation	-	-	3	-	3	-	-	1	-	-	7
	Reading or looking at books	2	-	-	-	7	-	-	-	-	-	9
	Colouring, drawing, painting	2	-	-	-	6	-	-	-	-	1	7
	Listening to stories	-	-	1	-	5	-	-	1	-	-	7
	Telling stories	-	-	2	-	-	-	-	-	-	-	2
	Cutting and pasting	1	-	1	-	4	-	-	-	-	1	5
	Watching TV	4	-	-	-	5	-	-	1	1	4	5

Category	Activities	Main Purpose								Importance for learning		
		Fun	Work or chores	Socialisation	Care	Educational	Exercise	Spiritual	Other	Not Important	Important	Very Important
Entertainment activities	Listening to music	6	-	-	-	3	-	-	1	1	3	6
	Singing	3	-	1	-	4	-	-	-	-	1	7
	Dancing	9	-	-	-	-	-	-	-	-	4	5
Chores	Assist in preparing meals	3	-	1	-	2	-	-	1	-	-	7
	Setting the table	1	2	-	-	1	-	-	-	-	-	4
	Cleaning the yard	1	4	1	-	-	-	-	-	-	1	5
	Washing socks and underwear	-	-	1	-	-	-	-	-	-	-	1
	Gardening	1	4	-	-	-	-	-	1	-	3	3
Spiritual activities	Praying	-	-	-	-	-	-	4	-	-	-	4
	Attending church	-	-	-	-	-	-	3	-	-	-	3
	Attending ancestral ceremony	-	-	1	-	-	-	-	-	-	-	1
Family activities	Visit family or traditional home	3	-	2	1	-	-	-	1	1	-	6
	Visiting family or friends in the neighbourhood	3	-	5	-	-	-	-	1	-	-	9
	Family gatherings	1	-	5	-	-	-	-	-	-	-	6
	Attending funerals	-	-	-	-	-	-	3	1	-	3	1
Community activities	Going to the ‘spaza’ shop	1	-	3	-	-	1	-	-	-	2	3
	Visiting a park	5	-	-	-	-	3	-	1	-	2	7
	Visiting shopping malls	1	-	3	-	-	-	-	2	1	3	2
	Eating out	-	-	6	-	-	-	-	-	-	2	4
	Attending weddings	-	-	1	-	-	-	-	1	-	1	1
	Attending parties	1	-	4	-	-	-	-	-	-	-	5
	Taxi ride	-	-	1	-	-	-	-	2	1	-	2

Appendix D: In-Person Consent Form to Participate in Primary Project

CONSENT TO PARTICIPATE IN A RESEARCH STUDY
VERSION 3

Title of the Research Project: "Tailoring Treatment Targets for Early Autism Intervention in Africa"

PRINCIPAL INVESTIGATOR: Dr Lauren Franz

ADDRESS: Division of Child and Adolescent Psychiatry, 46 Sawkins Road, Rondebosch, Cape Town, 7700 Tel: 021-685 4103

We want to see how a treatment for young children with autism that can be taught to parents works in South Africa. The name of this treatment is the "Parent Early-Start Denver Model". This treatment has been shown to work with parents and their children with autism in the United States. From working with you and your child we would like to learn how well this treatment can work for South African families. You will be taught different ways to play with your child to build your child's language and social skills. We will work with you and your child at your child's school for 1 hour per week for 12 weeks. We will do testing in clinic at 2 different times (before you start the study and after 12 weeks) to see how the treatment is working for you and your child. In the testing you will be asked to fill out questionnaires, play with your child, and your child will do some play based testing. Each testing session will last about 3 hours. After the 12-weeks of treatment, we may ask you to meet with us to tell us what you thought of the training we did.

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or health care provider any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied and that you clearly understand what this research is about. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Human Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town.** The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study will happen in a clinic in the Cape Town Metropolitan area.
- We want to understand more about how young children who live in South Africa develop, communicate, and play with their parent/caregiver.
- 60 parents/caregivers and their children will take part in the study.
- We will do testing in clinic once.

- In the testing you will be asked to fill out questionnaires, play with your child, and your child will do some play based testing. The testing session will last about 3 hours.
- To be part of the study your child must be between 18 and 72 months old and either have normal development or some developmental challenges.
- You must be over the age of 18, and have the legal right to sign this consent form for both you and your child, because your child is too young to sign this form.
- We will read through this form with you. Please ask if there any words that you do not understand. If you agree to be part of this study, you will sign this form.

Why have you been invited to participate?

- We are working with people who can help us understand understand more about how young children who live in South Africa develop, communicate, and play with their parent/caregiver. You are a parent or legal caregiver of a young child who lives in South Africa, who either has normal development or some developmental challenges. That is the reason we have asked you to be a part of this study.

What will your responsibilities be?

- We ask that you and your child come to the clinic to do testing once.
- We will ask that you come to the assessment on time and take part as fully as you can. This means that you will answer questions and perform tasks as fully and honestly as possible. If there are questions or activties you do not want to or cannot answer/engage in, you should say so. You do not have to participate in any activities that you do not want to.

Will you benefit from taking part in this research?

- We want you and your child to have a good time working with us. You will be able to talk with us about your child.
- You will help us learn how we need to change a treatment so it can work for South Africa families.
- We will give you a report on the all the testing your child had during the study.

Are there risks involved in your taking part in this research?

- There are no significant risks for you or child if you take part in this study. It may be hard for you to talk about some things. Your child might find some of the play activites confusing or boring. If there are questions you do not want to or cannot answer, or play that you do not want to do, you can say so. You do not have to do any activities that you do not want to.

- We will make every effort to keep your information confidential and protected. No information will be shared with anyone outside of the study team, including your health care providers. All documents and recordings will be stored in a locked filing cabinet or on a password protected computer. Your study information will be identified only by a number, not your name. Any documents containing your name and personal information will be kept separate from other study records, and will be stored in a secure way. If we write about this work, your identity will remain anonymous.
- The only time where we would not keep information confidential would be if we had reason to believe, that a) you are a potential harm to yourself or others; or, b) a child currently under age 18 had been physically, emotionally, or sexually abused, or emotionally neglected. We would be obliged to report such information to protect you and others. In such a case, the research staff member would report the information to the Project Director, who would then take immediate steps to intervene as appropriate. However, if the risk is imminent (i.e. about to take place) the research staff member will take action immediately.
- These are the main risks. Please tell us if you have any worries about this information.

A grant from the National Institutes of Mental Health in the United States will sponsor this study. Portions of the research team's salaries will be paid by this grant.

Because the study is funded by the National Institutes of Mental Health it may be audited. If information in this study is looked at in an outside review for an audit, it may be further disclosed by them and may not be covered by the federal privacy regulations.

A description of this clinical trial will be available on http://www.ClinicalTrials.gov. This web site will not include information that can identify you. At most, the web site will include a summary of the results. You can search this web site at any time.

Data from this study may be submitted to the National Database for Autism Research (NDAR). NDAR is a data repository run by the National Institute of Mental Health (NIMH) that allows researchers studying children's health to collect and share de-identified information with each other. A data repository is a large database where information from many studies is stored and managed. De-identified information means that all personal information (such as name, address, and phone number) is removed and replaced with a code number. With an easier way to share, researchers hope to learn new and important things about children's health more quickly than before.

During and after the study, we will send de-identified information to NDAR. Other researchers nationwide can then file an application with the NIMH to obtain access to your or your child's de-identified study data for research purposes. Experts at the NIMH who know how to protect health and science information will look at every request carefully to minimize risks to your privacy.

You may not benefit directly from allowing your information to be shared with NDAR. The information provided to NDAR may help researchers around the world treat future children and adults with mental illnesses so that they have better outcomes. NIMH will also report to Congress and on its web site about the different studies that researchers are conducting using NDAR data. However, you will not be contacted directly about the data you contributed to NDAR.

You may decide now or later that you do not want to share your or your child's information using NDAR. If so, contact Dr. Franz and she or a research study staff member will tell the NIMH Data Archive (NDA), which can stop sharing the research information. However, NDAR cannot take back information that was shared before you changed your mind. If you would like more information about NDAR, this is available on-line at https://nda.nih.gov.

Please indicate below whether you want us to share your or your child's de-identified information using NDAR for future research. (initial /date below)

________ Yes, I give permission that my study information can be stored in NDAR

_______ No, I do not want that my study information be stored in NDAR.

The testing will be sent to Duke University in the United States. It will sent to Duke University so:

- The person who is testing your child is doing it right.
- We can ways we can improve how we work with children and famlies.

Who else will be part of the study team?

- The study team will include a primary clinician who will work with you and your child. There will also be a different clinician who will do all the testing with you and your child.

If you do not agree to take part, what alternatives do you have?

- You are free not to take part or to withdraw at any time during the study. Your child's care will not be affected. You may continue to attend the the Divison of Child and Adolescent Psychiatry at the University of Cape Town. It would be helpful for the study team to let us know why you have decided not to take part, but you are free to not give a reason.

Who will have access to your medical records?

- If your child is in the group with developmental challenges, we will review your child's medical record at their Red Cross clinic so we can better understand what developmental challenges they may have.

Will you be paid to take part in this study and are there any costs involved?

- There will be no costs for you to take part in this study. The study staff will give you R250 for the testing session with you and your child come to. **We will also provide you and your child with a snack and juice, tea, or coffee.**

May you choose to not participate or to withdraw from this study?

- You may choose not to be in the study. If you agree to be in the study, you may withdraw from the study at any time. If you withdraw from the study, we will not ask for any more information from you. All data that have already been collected for the study will be kept.

How will videos be stored?

- The video recordings of the therapy sessions and the testing will be kept in a secure electronic folder at Duke University in the United States. The video recordings will not have the names of individuals or any information about the person or group that could be used to identify them. These videos will never be destroyed. The University of Cape Town Principal Investigator (Prof Petrus de Vries) and the Duke University Principal Investigator (Dr Lauren Franz) will be in charge of managing these videos.

In case of an emergency or if you feel you need to contact the Principal Investigator about questions or problems, you can do so by phoning: Dr. Lauren Franz at tel no 021-685 4103
(lauren.franz@duke.edu)

- You can also contact the Human Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town 021-4066338 (lamees.emjedi@uct.ac.za) if you have any concerns or complaints that have not been adequately addressed.

Declaration by participant

By signing below, I ……………………………….…………. agree to take part in a research study entitled: "Tailoring Treatment Targets for Early Autism Intervention in Africa"

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) .... on (*date*) ……….…………... 20__.

....

Signature of participant

Declaration by participant on behalf of their child

By signing below, I ………………………………….………. agree for the following child in my care ……………………………………………………for whom I am the parent or legal caretaker to be involved in the research study entitled: **"Tailoring Treatment Targets for Early Autism Intervention in Africa"**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I am over the age of 18, and have the legal right to sign this consent form for both myself and my child

Signed at (*place*) .... on (*date*) ……….…………... 20__.

....

Appendix E: Remote Enrolment and Consent Script to Participate in Primary Project

VERBAL CONSENT SCRIPT – TAILORING TREATMENT TARGETS FOR EARLY AUTISM INTERVENTION IN AFRICA

Hi. May I please speak to Name?

This is Staff Name calling from an EARLY AUTISM INTERVENTION study at UNIVERSITY OF CAPE TOWN. You/Your teacher at [INSERT NAME OF SCHOOL] indicated you are interested in participating in our EARLY AUTISM INTERVENTION study. Is now a good time to talk about this?

> ***If not***: Is there a better day or time? (Note day/time: __________________________.)
>
> ***If so***: Great. I'd first like to give you a little background on the study.

In this study *we want to see how a treatment for young children with autism that can be taught to parents in South Africa. The name of this treatment is the "Parent Early-Start Denver Model". This treatment has been shown to work with parents and their children with autism in the United States. From working with you and your child we would like to learn how well this treatment can work for South African families. You will be taught different ways to play with your child to build your child's language and social skills. We will work with you over the phone for 1 hour per week for 12 weeks. We will do testing at 2 different times (before you start the study and after 12 weeks) to see how the treatment is working for you and your child. In the testing you will be asked to answer questions and send us a video of you playing with your child. Each testing session will last about 1.5 hours and will take place over the phone. We will also ask you to send us a video of you and your child playing after each treatment session. After the 12-weeks of treatment, we may ask you to tell us what you thought of the training we did.*

Does this still sound like something you are interested in?

> ***If "no"*:** Ok, thank you for your time. If you change your mind, you can contact us at 0823193492. Have a wonderful day. Goodbye.
>
> ***If "yes"*:** Wonderful. I am now going to ask you some questions to make sure the study is a good fit for your child/family

Can you tell me how old [insert child's name] is?

> **If older than 72 months**: at this time we are unfortunately only enrolling children who are 5 years or younger. If you are interested in finding ways to participate in other projects, we can refer you to our research team at Centre for Autism Research in Africa (CARA).
>
> **If younger than 72 months**: Okay, good.

Does your child have any medical condition other than autism? Do they struggle to see or hear? Are they unable to walk, crawl and sit like other children their age? Did they ever hurt their head really badly? Do they suffer from seizures?

If "no": Okay, that's good.

If "yes" to any of the above: Determine if the condition can be classified as any of the following: 1) a significant sensory of motor impairment, 2) major physical abnormalities, 3) history of serious head injury and/or neurological disease, neurological disorder of known etiology (e.g Downs Syndrome).

If so: at this time we are unfortunately only enrolling children who have ONLY autism and no other conditions. If you are interested in finding ways to participate in other projects, we can refer you to our research team at Centre for Autism Research in Africa (CARA).

If not: Okay, good.

If no to all the above questions and child is younger than 72 months: OK, great. During this phone call, we will review the consent form, and then, if you still agree, you can give verbal consent to enroll your child. You must be the child's parent or legal guardian to enroll him/her in the study. We will also offer to send you a copy of the consent form via email for your records. Do you have any questions up to this point?

***If so**:* (Answer any questions.)

If not: Great. Let's get started. [Read and discuss the consent at length and in detail, answer any questions].

After consent form has been read and discussed: "Do you have any questions about the Early Autism Intervention/ESDM study or the consent form?"

***If not**:* Great. At this point, do you consent to enroll [child's name] in the Early Autism Intervention/ESDM study?

If not: Ok. If you change your mind at any point, please feel free to give us a call at 0823193492. Thank you for your time. Goodbye.

***If so**:* Ok, thank you. (Record information in database and fill out the consent note form entirely, noting anything unique to the enrollment.)

***Confirm telephonic baseline assessment date**:"* When will be a good time for one of our staff members to call you to ask some questions about your child's development? We need about 1.5 hours to talk in total."

When done: Thank you again for your time. As soon as we hang up I will send you an electronic copy of the consent form, for your records.

If applicable: If you wouldn't mind replying to the email, that will allow us to double check that we have your email addres correct and you did receive the form!

Thank you so much for your time. If you have any questions, feel free to call us back at 0823193492 or email us. Goodbye.

Appendix F: Faculty of Health Science Human Research Ethics Committee Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

16 July 2021

HREC REF: 441/2021

Prof P de Vries
Division of Child & Adolescent Health
Psychiatry & Mental Health
Email: Petrus.devries@uct.ac.za
Student: ndlmin004@myuct.ac.za

Dear Prof de Vries

PROJECT TITLE: TOWARDS NATURALISTIC DEVELOPMENTAL BEHAVIOURAL INTERVENTIONS FOR AUTISM IN AFRICA: CONTENT AND CONTEXTS OF CAREGIVER-CHILD DYADIC INTERACTIONS IN LOW-RESOURCE SOUTH AFRICAN ENVIRONMENTS-MSC CANDIDATE-MS MINKATEKO NDLOVU-SUB-STUDY LINKED TO 468/2019

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 July 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Ms M Ndlovu will also be involved in this study.

Please quote the HREC REF 441/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

HREC/REF441/2021sa

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.