Barriers and Facilitators to Implementing a Caregiver-Coaching Early ASD Intervention in South Africa

Chipo Belindah Theodorah Makombe

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Supervisor: Dr. Nokuthula Shabalala

Co. Supervisor: Dr. Lauren Franz

Signed by candidate

Signature: Date: 10 February 2019

Compulsory Declaration

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Abstract

Sub-Saharan Africa (SSA) has a scarcity of research on autism spectrum disorder (ASD) and available early interventions, as most of what is known about the disorder is from high-income countries. Early detection and intervention methods were found to have positive effects on developmental delays and to alleviate symptom severity in children with ASD or at risk of it. There is a need for scalable interventions in low-resource settings, which are characterised by a lack of highly-trained specialists, infrastructure and funding. This study explored the barriers and facilitators to implementing and sustaining a caregiver-coaching ASD early intervention, informed by the principles of the Early Start Denver Model (ESDM), adapted for South Africa and for delivery by non-specialists. The study also identified some changes that could be made to improve intervention adoption and sustainability. Nine multilevel stakeholders involved in the implementation of the caregiver-coaching intervention were purposively sampled, individual in-depth interviews were conducted, transcribed verbatim and thematically analysed. Major implementation facilitators included: ECD worker baseline ASD knowledge and experience; skills gained from the training received and coaching; clear in-session caregiver-coaching structure; value of strong team relationships; clear video illustration of intervention concepts; and the mastery and generalisation of skills by the ECD workers, ECD supervisors and caregivers. Implementation barriers included: the complexity of the intervention and coaching concepts; misalignment of ECD teacher training with the caregiver-coaching approach; logistical challenges; and mismatch of the video content with the South African context. Facilitators to sustain the intervention included: child outcomes; caregiver ‘buy-in;’ and competence; and the need for ongoing live supervision. Barriers to sustaining the intervention included: structural issues of poverty, transportation and unemployment. Positive child and caregiver outcomes could be offset by larger contextual and system-level issues such as poverty and the need for ongoing support, supervision and local coaching materials in South African languages. The results will inform tailoring of the intervention training and supervision approach for a larger pilot study.

Keywords: Autism Spectrum Disorder; South Africa; Early Intervention; Caregiver Coaching; Early Start Denver Model; Early Childhood Development Worker

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder which impairs functioning in social communication and interaction, and is seen in restricted and repetitive behaviour patterns (American Psychiatric Association, 2013; Gray & Tonge, 2001; Hazen, McDougle, & Volkmar, 2013; Hyman, 2013). ASD is a term that encompasses autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorders (PDDs) not otherwise specified (NOS) (American Psychiatric Association, 2013; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012). The causes of ASD are not known, but it is ubiquitous and occurs cross-culturally, with onset before the age of three and persistent impairment, although severity varies from child to child (American Psychiatric Association, 2013; Elsabbagh et al., 2012; Khan et al., 2012). ASD cannot be diagnosed with a medical test, making it difficult to detect, but research shows that a diagnosis can be given as early as two years old (Centers for Disease Control and Prevention, 2018a).

The vast majority of knowledge about ASD originates from western studies, and there are large gaps in the research or prevalence data on ASD in Sub-Saharan Africa (SSA) (Abubakar, Ssewanyana, de Vries, & Newton, 2016; de Vries, 2016; Morris et al., 2011; Sanders & Haines, 2006). The United States has just over 323 million people and their current ASD prevalence rate is 1 in 59 children, a sharp increase from 1 in 68 children in 2012, while SSA, with a recorded population of 1.033 billion people (Centers for Disease Control and Prevention, 2018b; World Bank, 2018) has no population-based research, and very limited data on ASD diagnosis and available interventions (Bello-Mojeed, Bakare, & Munir, 2014; Black et al., 2017; de Vries, 2016). Thus, the available empirical research on SSA is still minimal, with only 53 peer-reviewed ASD articles as of 2016 (Franz, Chambers, von Isenburg, & de Vries, 2017).

Despite the scarce data, there is a strong likelihood of high ASD incidence rates in low- and middle-income countries (LMIC), partly due to the limited provision of support services (Bello-Mojeed et al., 2014; Samms-Vaughan, 2014). However, several studies have established that there is a need for evidence-based research that would identify ASD gaps and contribute towards building capacity, whilst also expanding access to early intervention care for families and children affected (Blake et al., 2017; de Vries, 2016; Klasen & Crombag, 2013; Morris et al., 2011; K. S. Wallace & Rogers, 2010; Yousafzai, Lynch, & Gladstone, 2014).

Past studies, largely conducted in better-resourced settings, established that early detection and intervention reduced ASD symptom severity in children (Bradshaw, Steiner, Gengoux, & Koegel, 2015; Devescovi et al., 2016; Rogers et al., 2006; Schreibman et al., 2015; Vismara & Rogers, 2008; Vivanti et al., 2014; Wetherby et al., 2014; Zachor & Curatolo, 2014). Similar findings and benefits were recorded in a few LMIC studies (Harrison, Long, Manji, & Blane, 2016; Maulik & Darmstadt, 2009; Rahman et al., 2016), but very little evidence was discovered that was linked to early interventions, training and collaboration amongst health professionals in the resource-strained areas (Abubakar, Ssewanyana, & Newton, 2016; Engle et al., 2011; Franz et al., 2017). There is still a paucity of specialists, low-cost treatment and accessible services in LMIC, exacerbated by a lack of government, health and social development aid in establishing mental healthcare facilities and supporting early childhood development (de Vries, 2016; Franz et al., 2018; Wannenburg & Van Niekerk, 2018).

Children who present with ASD-like symptoms behave, learn and respond differently to their environment, and as a result require significant help to function within society (American Psychiatric Association, 2013; Centers for Disease Control and Prevention, 2018b). Current early intervention programmes that support children developed in well-resourced countries are costly and traditionally delivered by highly-trained professionals (Bello-Mojeed et al., 2014; Estes et al., 2015; Hastings, Robertson, & Yasamy, 2012; Studer, Gundelfinger, Schenker, & Steinhausen, 2017), and studies typically do not explore and consider factors that would impact implementation in countries with diverse populations and less-skilled professionals. To this end, the identification of barriers and facilitators to implementing interventions developed in high-income countries (HIC) for low- and middle-income settings is crucial for identifying scalable treatment methods (Cheremshynski, Lucyshyn, & Olson, 2012; Harrison et al., 2016; Yamey, 2011).

Starting with a discussion on the prevalence of ASD, Chapter 2 presents a review of the relevant literature, including ASD aetiology, symptoms and secondary conditions commonly associated with ASD. The chapter then discusses the unique complexities of children diagnosed with ASD, and the impact this has on their families. This is followed by a discussion on the importance of early ASD interventions. The chapter provides examples of early interventions developed for ASD, and a description of the Early Start Denver Model (ESDM), the early intervention which forms the basis of this study. The chapter also covers early intervention for South Africa and issues of early intervention accessibility in community settings. This is followed by a review of specific non-specialist delivered caregiver coaching studies. The chapter concludes by discussing barriers and facilitators to early ASD intervention implementation in South Africa.

Chapter 3 describes the research methodology, starting with the rationale for using a qualitative approach. This is followed by a brief background of the ESDM adaptation process, a description of the video material that was used, and of the subsequent training of non-specialist Early Childhood Development (ECD) workers. The chapter then provides an outline of the setting and sampling procedures for this study, before discussing the implementation process of the caregiver coaching at the schools, along with an outline of how data was collected. The chapter concludes with a description of the thematic analysis used to analyse the data, and a section on reflexivity and details of ethical clearances obtained for this study and the larger pre-pilot study.

Chapter 4 presents the themes and sub-themes of the study, while chapter 5 is a summary of the findings, a discussion of how the findings relate to the relevant literature, and the limitations and strengths of the study with implications for future research.

Chapter 2: Literature Review

The aim of this chapter is to provide a review of the literature on ASD as a lifelong condition, and the importance of early interventions, with a focus on identifying barriers and facilitators to early ASD intervention implementation and sustainability. The first section discusses ASD prevalence data, the key ASD indicators, comorbidities, societal costs and reviews the diagnosis in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) (American Psychiatric Association, 2013). This is followed by a discussion on the importance of early intervention strategies and the psychological impact of ASD on families affected.

The next section explains the importance of ASD treatment strategies, and the benefits associated with a group of early intervention approaches called Naturalistic Developmental Behavioural Interventions (NDBIs) (Schreibman et al., 2015) in high-resource settings. Findings from NDBI implementations are explained, followed by a discussion of the Early Start Denver Model (ESDM), an evidence-based early intervention approach, one of the NDBIs and the intervention used in this study. The next sections explore studies conducted in South Africa on early intervention, the process of accessing care in the Western Cape Province and contextual factors affecting such low-resourced environments.

Following this is a discussion on the difficulties associated with accessing early interventions in community settings, while the next section provides an account of non-specialist delivered caregiver coaching early ASD intervention implementation, the proposed treatment strategy of training early childhood development workers (ECD) to deliver early intervention in less-resourced settings. The last section discusses barriers and facilitators to early ASD intervention implementation in South Africa, where there is limited research and access to clinical and educational services. The review is important for understanding the available evidence on early ASD interventions in LMIC.

Autism spectrum disorder and comorbidities

The estimated global prevalence data for ASD is 1 in every 160 children (Elsabbagh et al., 2012; World Health Organisation, 2017), and while the US prevalence is 1 in 59 (Centers for Disease Control and Prevention, 2018b), other known estimates include 1 in 93 in South Asia (Hossain et al., 2017) and 1 in 38 children in South Korea (Autism Speaks, 2011). There is currently no ASD prevalence data in sub-Saharan Africa (Franz et al., 2017) yet most at-risk children live within this part of the world (Kieling et al., 2011). More boys than girls are diagnosed with ASD, at a ratio of 4:1, and in the US the probability of children being diagnosed with ASD went up by 15% from 1 in 68 in 2010 to 1 in 59 in 2014 (Centers for Disease Control and Prevention, 2018b). The CDC advocates for the importance of early detection and early intervention, which provides timely support for the developmental growth of the child (Centers for Disease Control and Prevention, 2018a).

ASD aetiology is linked to environmental and genetic factors (American Psychiatric Association, 2013). The environmental risk factors include a child born to older parents, low birth weight or exposure to prescription medication (American Psychiatric Association, 2013). Genetic factors include an increased risk for children with a sibling with ASD, with an estimated 37–90% chance of ASD in twin studies (American Psychiatric Association, 2013; Centers for Disease Control and Prevention, 2018a). ASD symptoms include social communication deficits, and restricted and repetitive behaviour patterns of behaviour or interests (American Psychiatric Association, 2013). Comorbidities can include epilepsy, intellectual disability, oppositional defiant disorder, attention-deficit/ hyperactivity disorder, anxiety, and language, sleep and mood disorders, amongst other conditions (American Psychiatric Association, 2013; Carlson et al., 2013; Goodwin, Matthews, & Smith, 2018; May et al., 2018). Comorbidities may further adversely impact a child’s occupational, social, academic, and emotional functioning (American Psychiatric Association, 2013).

Individuals with ASD typically require early intervention and additional supports, including occupational therapy, speech therapy, physiotherapy and psychological interventions to address developmental challenges (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Guler, de Vries, Seris, Shabalala, & Franz, 2017; Wannenburg & Van Niekerk, 2018). This consequently puts extreme pressure on resources and time, demanding extra childcare and financial support from the family (Cidav et al., 2017; Hastings et al., 2012; Russa, Matthews, & Owen-DeSchryver, 2015; Ryberg, 2015; Sen & Goldbart, 2005). While therapeutic services are very costly (Buescher, Cidav, Knapp, & Mandell, 2014; Knapp, Romeo, & Beecham, 2009; Olagunju et al., 2017) according to Cidav and colleagues early intervention is a cost-effective approach (Cidav et al., 2017).

Early ASD interventions

Numerous meta-analyses and systematic reviews have concluded that early intensive intervention has positive effects on development in young children with ASD (Beaudoin, Sébire, & Couture, 2014; Eldevik et al., 2010; Hampton & Kaiser, 2016; Lane, Lieberman-Betz, & Gast, 2016; Reichow, 2012; Virués-Ortega, 2010), although effects are greater for some children than others (Sallows & Graupner, 2005). Early intervention is important for numerous reasons. First, during the first six years of a child's life the brain is optimally primed to develop language and social skills (Braddock & Twyman, 2014; Brian et al., 2017; Mubaiwa, 2008; Vivanti & Dissanayake, 2016). Second, the growth of language skills enhances other crucial areas of cognitive development and adaptive behaviours (Oono, Honey, & McConachie, 2013; Perry et al., 2008), and decreases challenging behaviours (Fulton, Eapen, Črnčec, Walter, & Rogers, 2014; Symon, 2005; Vismara & Rogers, 2008). Third, early detection of and intervention for ASD can reduce long-term costs for special education, supported employment and sheltered living (Cidav et al., 2017; Estes et al., 2015). Fourth, comorbidities such as epilepsy, ADHD, and related secondary conditions can be detected, treated and monitored (Goodwin et al., 2018; Gray & Tonge, 2001; Mubaiwa, 2008; Rahman et al., 2016; Springer, van Toorn, Laughton, & Kidd, 2013). Finally, caregivers can be empowered early in their child's life with skills to support their child's development (Joseph & Muralidhar, 2018).

Caregivers of children with ASD may themselves experience stigma, social exclusion, and high levels of parental stress and mental health challenges (Fulton et al., 2014; Olagunju et al., 2017; Yousafzai et al., 2014). The World Health Organisation (WHO) has called for research that creates a better understanding of the elements that would enable the development of evidence-based, lower cost interventions for people with ASD, as early intervention provides the best possibility for improving the lives of children with ASD and their families (World Health Organisation, 2013, September 16-18). This has resulted in increasing efforts to enrich the lives of those living with ASD in LMIC such as South Africa (Khan et al., 2012; Kieling et al., 2011; Patel, Kieling, Maulik, & Divan, 2013). Some of the barriers to scaling up early ASD interventions in LMICs could be offset by adopting non-specialist-delivered interventions, as a means of providing easily accessible and cost-efficient services (de Vries, 2016; Franz et al., 2017).

Early intervention with Naturalistic Developmental Behavioural Interventions (NDBI)

A class of early ASD interventions developed for young children are known as Naturalistic Developmental Behavioural Interventions (NDBIs). NDBIs are implemented in natural settings (for example, the child's home); allow for shared control of materials or the activity between the child and therapist/caregiver; use natural contingencies (for example, objects that the child finds motivating and has requested are used to reinforce behaviours being taught); and use various behavioural strategies to teach developmentally appropriate skills (for example, modelling or prompting) (Schreibman et al., 2015).

Caregivers can be coached to implement NDBI strategies with their young children (Estes et al., 2014; Oono et al., 2013). Because NDBIs can be used in less-structured home settings and strategies can be integrated into daily interactions with the child (Ingersoll & Wainer, 2013), NDBIs may reduce the burden of therapy on family time, travel, and cost (Brian et al., 2017). Caregiver NDBI intervention knowledge and skills may help increase child learning opportunities during caregiver-child interactions (Vismara & Rogers, 2008), and boost feelings of caregiver competence (Joseph & Muralidhar, 2018; Stahmer et al., 2017). Examples of caregiver-implemented NDBIs include the Early Start Denver Model (ESDM) (Rogers & Dawson, 2009), Project ImPACT (Improving Parents As Communication Teachers) (Ingersoll & Wainer, 2013), and Joint Attention Symbolic Play Engagement and Regulation (JASPER) (Shire et al., 2017).

Early Start Denver Model (ESDM)

The Early Start Denver Model (ESDM) is an NDBI and was the first comprehensive evidence-based early intervention for young children with ASD, which adopts a relationship-focused approach while targeting core ASD core symptoms through developmentally sensitive teaching (Dawson et al., 2010). The intervention facilitates child engagement in play and routine-based activities, and integrates teaching of developmentally appropriate skills during these interactions (Dawson et al., 2010; Rogers & Dawson, 2009; Rogers et al., 2012).

In 2010 Dawson published the results of a randomized controlled trial (RCT) on ESDM, with 48 children diagnosed with an ASD. Participants between the ages of 18-30 months were randomized into two groups (ESDM: n=24; "treatment-as-usual" community group: n=24). The study reported significantly greater gains in language and developmental quotient and greater decreases in parent-reported symptoms of ASD in the group who received intensive ESDM treatment. This was the first early ASD intervention RCT grounded in developmental science (Dawson et al., 2010). Thirty-nine children who participated in this RCT were later assessed at age 6 years. The follow-up study suggested that gains from early intensive ESDM intervention were maintained 2 years later. Notably, at follow up, the ESDM group were receiving significantly fewer services than the community treatment group (Estes et al., 2015). Importantly, the costs associated with intensive ESDM treatment were offset within a few years after intervention due to reductions in other service use and associated costs, suggesting that early intensive intervention with ESDM was a cost-effective approach (Cidav et al., 2017).

The parent or caregiver-delivered version of the Early Start Denver Model (P-ESDM) is an emerging NDBI (Rogers et al., 2012). The first RCT of a 12-week, low-intensity P-ESDM program did not show any advantage over a community intervention group, in terms of child developmental outcomes (Rogers et al., 2012). In the next RCT, changes were made to intervention dosage, learning tools, and motivational interviewing techniques (Rogers et al., 2018). This RCT demonstrated greater gains in caregiver intervention techniques compared to the initial P-ESDM approach, in addition to a significant relationship between caregiver change in intervention techniques and the rate of child improvement on developmental outcomes and ASD symptoms (Rogers et al., 2018).

Early intervention for ASD in South Africa

In a 2017 scoping review, Franz and colleagues identified 11 intervention studies on ASD in sub-Saharan Africa (Franz et al., 2017). Nine of these publications were from South Africa, one was from Kenya, and one was from Nigeria. From the minimal ASD intervention literature in SSA (Franz et al., 2017), none explored the development or implementation of early ASD interventions on the continent. In South Africa, the Western Cape province is thought to be one of the better resourced in terms of health care and education (Statistics South Africa, 2017). However, the majority of the population has very limited access to early detection and intervention services (Franz et al., 2018). The procedure for accessing ASD concerns starts at a community clinic, and then a referral is made for specialist opinion at a neurodevelopmental clinic affiliated with a tertiary hospital. This diagnostic process takes between 9-18 months. Once a diagnosis has been made the child’s name is placed on a Western Cape Department of Education Department’s provincial ASD waiting list for school placement, and referred for therapeutic intervention. A speech or occupational therapist may provide therapy for 30-minute sessions once every 4-6 weeks, whilst the majority of ongoing care is left to the families (Franz et al., 2018; van Schalkwyk, Beyer, & de Vries, 2015). In a recent study in the Western Cape Pillay and colleagues found that 940 children with ASD were in a Special Education school, 744 were on the waiting list and 646 of the children on the waiting list were younger than 7 years (Pillay, Duncan, & de Vries, 2017, September). Springer and colleagues in their Western Cape tertiary hospital developmental clinic study established that a large profile of children at the clinic presented with severe ASD-like traits, that needed urgent and consistent medical, social and educational support (Springer et al., 2013).

Additionally, cultural beliefs, language barriers, unemployment, limited education or knowledge of ASD, stigma, lack of social support and space in the home, and poverty may affect access to and utilization of available resources (Chambers et al., 2017; Guler et al., 2017; Harrison et al., 2016; Schlebusch, Dada, & Samuels, 2017; Sen & Goldbart, 2005; Swart, Engelbrecht, Eloff, & Pettipher, 2002). Moreover, several special education and healthcare institutions in South Africa already operate at capacity (Mubaiwa, 2008; Ruparelia et al., 2016). Professionals may also have insufficient knowledge about ASD (Tekola et al., 2016; Wannenburg & Van Niekerk, 2018). These experiences may further predispose caregivers to stress, anxiety, low self-esteem, frustration, seclusion and depression (Estes et al., 2014; Hastings et al., 2012; Sen & Goldbart, 2005; Yousafzai et al., 2014). Caregiver feelings of helplessness have also been attributed to a lack of emotional, social, and financial support (Mthombeni & Nwoye, 2018; Wetherston et al., 2017). Upskilling parents in evidence-based early intervention strategies and providing psychoeducation about ASD may have positive benefits for both the family and their child (Baker-Henningham, 2014; Schlebusch et al., 2017; Stahmer et al., 2017).

Accessibility of early ASD intervention in community settings

While early ASD intervention may yield clinically significant results in RCTs, their success at a community-level is dependent upon many factors that impact intervention feasibility and sustainability (Cidav et al., 2017; Odunsi, Preece, & Garner, 2017; Pickard, Kilgore, & Ingersoll, 2016; Rocha, Schreibman, & Stahmer, 2007; Sen & Goldbart, 2005). Examples of these factors include: the need for community collaboration in intervention development; the degree of language ‘fit’ between intervention providers and the community they serve; parent/caregiver time and motivation to receive early intervention services; as well as access to appropriate physical resources such as toys used in therapeutic approaches as well as sufficient physical space in the home (Odunsi et al., 2017; Rocha et al., 2007). Additional implementation barriers, particularly relevant to low resource settings include lack of sufficient healthcare or educational infrastructure and institutional support (Baril & Humphreys, 2017; Guler et al., 2017; Murillo, Shih, Rosanoff, Daniels, & Reagon, 2016; Wannenburg & Van Niekerk, 2018).

In an early intervention study by Colombi et al. (2018) in Italy, the authors note that early ASD intervention techniques can be mastered by parents/caregivers and may be culturally acceptable in some areas of the world, outside of the United States where most of these intervention approaches were developed. However, post-implementation data suggests that despite positive benefits for children with or at risk of ASD, barriers to the sustainability of adopted interventions in community settings still exist (Baril & Humphreys, 2017).

Interestingly, literature from high-income countries shows early intervention accessibility is limited for some parents due to health disparities (Buescher et al., 2014; Knapp et al., 2009; Studer et al., 2017). For example, in better-resourced areas of the world such as the US (Cidav et al., 2017) and Switzerland (Studer et al., 2017), underprivileged parents still battle to access early interventions, much like families and children with far fewer resources in LMIC (Elsabbagh et al., 2012; Samms-Vaughan, 2014). These high-income and LMIC commonalities underline the importance of and need for lower cost, non-specialist delivered, culturally-appropriate and community-based interventions (Yousafzai et al., 2014).

Non-specialist delivered caregiver coaching early ASD intervention

There is a significant scarcity of trained professionals in SSA with the therapeutic capacity to meet population needs for early ASD intervention (de Vries, 2016; Franz et al., 2017). Ruparelia and colleagues (2016) noted that the ratio of ASD specialists to the population in SSA was “very low or non-existent” (p.1022). This finding underscores global mental health reports that have long called for strategies to overcome limited access to resources and trained specialist in LMICs (Elsabbagh et al., 2012; Ertem et al., 2009; Sen & Goldbart, 2005; Swiezy, Stuart, & Korzekwa, 2008; S. Wallace et al., 2012; Yamey, 2011; Zachor & Curatolo, 2014). The concern around care could be met through collaboration and capacity building efforts between specialists and non-specialists (Kieling et al., 2011; Morris et al., 2011; Murillo et al., 2016; Patel, Flisher, Nikapota, & Malhotra, 2008).

In addition, community and family collaboration can create a platform to adapt intervention models and assess their appropriateness for at-risk children in LMIC (Engle et al., 2011). The implementation of non- specialist early ASD intervention in SSA could be a progressive step towards enhancing the quality of life for families affected by ASD. In a meta-analysis published by Reichow and colleagues, the authors concluded that there was sufficient evidence to support the delivery of psychosocial interventions by non-specialist providers to children who have intellectual disabilities or lower-functioning ASD (Reichow, Servili, Yasamy, Barbui, & Saxena, 2013). In this study, they defined ‘non-specialist’ as anyone who was not a psychiatrist, psychologist, psychiatric nurse practitioner, speech and language pathologist, occupational therapist, or a physical therapist. Importantly, only two of the studies included in the meta-analysis were from LMICs and conducted with young children with ASD. In those two studies, the ‘non-specialist’ was a qualified teacher and a community therapist who provided intervention directly to the children, without direct caregiver involvement (Tsang, Shek, Lam, Tang, & Cheung, 2007; Wong & Kwan, 2010).

While the World Health Organization Resolution on ASD (2014) and the mental health Gap Action Programme (mhGAP) for developmental disabilities (World Health Organisation, 2015) strongly recommends that parent/caregiver education and skills training be an essential component after an ASD diagnosis, to date, only two published studies have examined NDBI-informed caregiver coaching in non-Western settings (Rahman et al., 2016; Zhou et al., 2018). While both of these studies reported improvements in child and caregiver outcomes as a result of the caregiver coaching interventions, caregiver coaches in both studies had at least a university-level Bachelor’s degree. This is a workforce that is unlikely to be scalable in low-resource environments.

Barriers and facilitators of early ASD intervention implementation in South Africa

The recommendation for caregiver skills training set out by the WHO (World Health Organisation, 2013, September 16-18, 2015) would need to embrace a task shifting approach from specialist providers to non-specialist providers in order to be feasible in LMICs like South Africa. Pilot work is currently underway in South Africa to adapt and assess the impact of a 12-week, 1-hour per week caregiver-coaching ESDM-informed early ASD intervention delivered by non-specialist Early Childhood Development (ECD) workers (Franz et al., 2018, May). Formative work with caregivers of young children with ASD, and Western Cape policy makers and senior clinicians has been conducted (Franz et al., 2018; Guler et al., 2017). Caregiver-identified contextual factors relevant to early ASD intervention has informed the adaptation of the caregiver-coaching intervention. In-depth interviews with Senior Management in Health, Education, Social Development and the non-profit sector has identified a platform for ASD-specific early intervention delivery. It appears that at this time in South Africa, ASD early intervention is more closely aligned with Education department goals and their non-specialist ECD workforce than with Health or Social Development goals (Franz et al., 2018). For this reason, ECD workers, employed by the Education department have been targeted to deliver this caregiver-coaching intervention.

While early interventions are traditionally delivered by trained specialists (Eapen, Črnčec, & Walter, 2013; Vivanti, Dissanayake, Zierhut, & Rogers, 2013), in countries such as South Africa with limited capacity, specialists are scarce, inaccessible and costly, and therefore cannot address population needs for early ASD intervention (de Vries, 2016; Patel et al., 2008; Ruparelia et al., 2016) . While growing research supports the shift from specialist to non-specialist delivered intervention in order to address early childhood developmental needs, not much is known about barriers or facilitators to implement and sustain such early intervention in LMICs such as South Africa (Franz et al., 2017). Non-specialists may not be adequately trained for learners with special education needs, let alone ASD (Swart et al., 2002). In addition, training in new methods of working with young children may be challenging for non-specialists and caregivers (Alli, Abdoola, & Mupawose, 2015; Ntombela, 2011; Swart et al., 2002). Importantly, participant perceptions help guide intervention development and sustainability which may assist with widespread adoption (Vivanti et al., 2018). The experiences of participants involved in intervention implementation may help identify the ‘fit’ of the new intervention with the new setting, and intervention components that should be further adapted to enhance uptake and sustainability.

For South Africa, implementation of a caregiver-coaching ESDM-informed early ASD intervention delivered by non-specialists is therefore more likely to be successful if key barriers and facilitators to intervention implementation are identified (Curran et al., 2012; Puchalski Ritchie et al., 2016; Sanders & Haines, 2006; Yamey, 2012). A qualitative process evaluation of barriers and facilitators to implementation will draw on the experiences of the participants and identify wider implementation challenges and adaptations needed for future studies (Curran et al., 2012).

Aim of the study

This study investigated perceived facilitators and barriers of a non-specialist-delivered caregiver-coaching intervention, informed by ESDM principles and adapted for South Africa. The study adopted a qualitative approach in exploring: (1) barriers and facilitators to implementation; (2) barriers and facilitators to the sustainability of the ESDM-informed early intervention after the study was completed; and (3) changes needed to improve the adoption and sustainability of the intervention in South Africa.

Significance of the study

The majority of families raising a young child with ASD in South Africa face numerous challenges (Guler et al., 2017; Mthombeni & Nwoye, 2018). These may include a lack of physical resources or emotional support, the financial strain of specialist childcare, limited knowledge amongst caregivers and professionals, difficulty accessing appropriate healthcare services, education or special needs schools, and societal stigma (Fleisch, Shindler, & Perry, 2012; Guler et al., 2017; Mthombeni & Nwoye, 2018; Schlebusch et al., 2017). Early intervention for ASD with evidence-based principles can positively affect both the child and their family (Rogers et al., 2014; Schlebusch et al., 2017). Caregiver coaching delivered by non-specialist providers may hold the key to reducing societal costs associated with ASD and improving quality of life for both the child and their family. This study will, therefore, discuss what factors act as barriers and facilitators to implementing an early ASD-intervention, delivered by non-specialists.

Chapter 3: Methodology

This chapter will outline the methods used in the study, and begins with a description of the interpretative qualitative process evaluation research approach. This is followed by a brief summary of the ESDM-informed intervention adapted for South Africa. The focus then turns to the data collection and data analysis processes, including the setting, sample and procedures of this study, before concluding with a discussion on the reflexivity of the researcher and ethical considerations.

Research Design: Motivation for adopting a Qualitative research approach

Qualitative research is a method of enquiry used to study and explain human problems and experiences in their natural setting (Creswell, 2014). It is interpretive, involving various methods of data collection, such as participant observation, examining documents, and conducting interviews (Denzin & Lincoln, 1998), and the researcher is seen as an instrument of data collection, attempting to make meaning of nuanced constructs and the information provided by participants (Creswell, 2007). Furthermore, it is descriptive in nature, both open-ended and non-numerical, allowing for greater expression and an interpretation of the information provided by participants (Creswell, 2014). This would not necessarily be possible with a quantitative approach because of the complexity and exploration needed to understand personal human experiences, settings or contexts (Creswell, 2007, 2014; Denzin & Lincoln, 1998). Although the approach is rigorous, contextual data collected qualitatively is more easily captured, understood and interpreted (Creswell, 2014).

Qualitative methodology is commonly used in implementation studies to understand healthcare knowledge and to identify key implementation challenges (Curran et al., 2012; Guler et al., 2017). In this study, the purpose of the pre-pilot was to assess the feasibility of the intervention training and supervision. This qualitative process evaluation study aimed to elicit participant perceptions of the South African-adapted ESDM-informed caregiver-coaching implementation process, and their experience of the early intervention training and implementation is better explained by a qualitative research approach than by a quantitative approach.

Study credibility and dependence was established and maintained through constant checking of the research design and study aim to ensure transferability and congruence between the literature review, data collected and analysis.

Research Type

The research type selected for the study was phenomenological in nature. This approach aims to explore human experiences, actions, words, and creations in relation to the contexts in which they occur around a particular phenomenon (Terre Blanche & Durrheim, 1999; Tesch, 1990). For this study, this meant intersubjective descriptions of themes extracted from participant lived experiences while suspending researcher preconceptions, listening to information provided, understanding the participant and allowing their account to speak for itself (Terre Blanche & Durrheim, 1999; Tesch, 1990). The researcher was interested in developing a greater understanding of people's lived experience of an early intervention for ASD, from the first time they learnt the intervention, and implemented it with caregivers and their children with ASD. By being part of the training and implementation, the researcher was empathic in her understanding of how the participants interpreted their individual experiences throughout the duration of the pre-pilot.

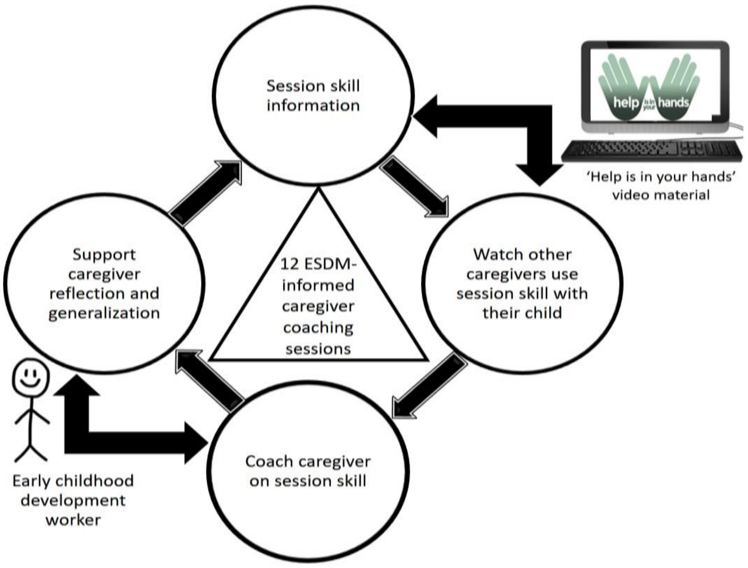
Training in and implementation of the South African-adapted ESDM caregiver-coaching intervention

In order to understand the intervention, it is necessary to give a brief summary of the adaptation and training as a context for understanding the study. The ESDM-informed caregiver coaching intervention adaptation process followed for South Africa is available (see Appendix A). After getting permission to conduct the study and identifying two ECD workers from the two schools, the ECD workers received four days of training in the South African-adapted ESDM-informed caregiver coaching. The ECD workers' supervisors attended the training but did not participate in caregiver-coaching activities, which was conducted by a certified ESDM trainer and three local certified ESDM therapists. The South African-adapted intervention utilises Community "Help is in your hands" ESDM videos and materials (Rogers, Vismara, Dawson, & Stahmer, 2017), which are currently being piloted in rural, low-resource areas of the United States. The "Help is in your hands" Community ESDM videos are a web-based tool to help caregivers build their children's social and communication abilities, and consist of four modules of four lessons each (16 videos) that include didactic information on strategies to increase child attention to people, child communication, learning and engagement in daily activities using social routines, and employing the ABCs of learning to teach new behaviours. The videos focus on using strategies in daily routines, and are narrated and animated, with very little text, and controlled reading levels. In the ECD worker training, the “Help is in your hands” Community ESDM videos provided most of the didactic instruction in ESDM strategies and caregiver coaching. The didactic input was combined with seven sessions of caregiver coaching practice in a caregiver-child dyad, where ECD workers received live supervision as they practised coaching the caregiver.

Implementation at the schools/Caregiver coaching

All coaching sessions took place at the collaborating schools. Figure 1 displays the structure for the 12 sessions of caregiver coaching. The session skill is introduced by the appropriate “Help is in your hands” Community ESDM videos (Rogers et al., 2017), and the ECD workers then coach caregivers on the session skill during the activity and support caregiver reflection after each activity. The final part of the training addresses caregiver questions and supports reflections on how the skill taught can be generalised during different activities in daily life, such as bathing, meal-times and toy activities. Each ECD worker was supported in-session by a certified ESDM therapist, and at the end of every session, caregivers were given copies of the “Help is in your hands” Community ESDM videos to watch at home on their own time, and a ‘refrigerator list’ that summarised the session skill (see Figure 1).

Figure 1. Caregiver-Coaching Session Structure



Setting

The study was conducted in Cape Town, a city of 3.7 million people in the Western Cape Province of South Africa (Statistics South Africa, 2012). The diverse population is made up on 42% Coloured (a South African term used to describe people of mixed race), [1] 39% Black African, 15.7% White, 1.4% Indian and Asian, and 1.9% described as ‘other’ (Statistics South Africa, 2012). South Africa has 11 official languages, which are Afrikaans, English, isiNdebele, isiXhosa, isiZulu, Northern Sotho, Southern Sotho, Setswana, SiSwati, Tshivenda and Xitsonga. The most widely-spoken language in Cape Town is Afrikaans (41.4%), followed by isiXhosa (28.7%), English (27.9%), and a small proportion who speak other languages (1.9%) (Statistics South Africa, 2012). The unemployment rate is 23.8%, and 35.7% of the population live below the poverty line, with about 20.5% living in informal dwellings (Statistics South Africa, 2012). 38.6% have some secondary education, while 1.8% have no schooling (Statistics South Africa, 2012), and race and educational attainment are key determinants of resource availability and accessibility. The unequal distribution of and access to resources have been attributed to the impact of apartheid policies on people of colour in South Africa (Christopher, 2003; Ntombela, 2011). Having a disability, poverty, and the country’s racialised history are all barriers to accessing basic education and health services, and underprivileged groups benefit least from the economy (Fleisch et al., 2012). A high number of non-verbal children at risk of ASD were reported in the province, with the majority being Black African (Springer et al., 2013), while in the education sector, there are over 700 children with ASD or at risk of it on a consolidated ASD waiting list for the province (Pillay, Duncan, & de Vries, 2018, May). The majority of children in South Africa who do not have a school placement, and who are therefore excluded from the system, are from poorer areas and backgrounds (Fleisch et al., 2012). Poverty determines access to health and healthcare (Mayosi & Benatar, 2014). The Western Cape has insufficient access to special education schools, ASD assessments, and early interventions, government support, therapists and interventions are costly (Franz et al., 2017; Guler et al., 2017; Pillay et al., 2018, May). Consequently, less-severe cases of suspected ASD are not referred for early intervention (Springer et al., 2013).

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[1] This population classification system of categorising people is as per the repealed Population Registration Act of 1950, which included the contested division of racial groups. The terms are still in use: the Employment Equity Act (1998) uses the terms to implement and maintain affirmative action, and Statistics South Africa (SSA) uses the terms to map diversity and denote ethnic groups in South Africa (Christopher, 2003).

The South African-adapted ESDM-informed caregiver-coaching training took place at the Division of Child & Adolescent Psychiatry (DCAP) in the Department of Psychiatry and Mental Health at the University of Cape Town. The caregiver coaching took place at two schools that belong to the Western Cape Education Department (WCED), and both schools employ ECD workers and provide autism-specific educational services for children across all demographic lines. One of the schools is located closer to the centre of town, while the second school is in the Northern Suburbs.

Sample

As shown in Table 1 below, nine participants (8 female, 1 male) were recruited from DCAP and the two WCED schools through purposive sampling. Participants included certified ESDM therapists (n=3), ECD workers (n=2), ECD school supervisors (n=2), and caregivers (n=2) with their young children. Both children in the study are currently on a WCED provincial ASD waiting list for school placement. One caregiver-child dyad withdrew from the study due to a lack of reliable transportation, so another caregiver-child dyad was recruited from the same school in order for two such dyads to participate in the pre-pilot.

Table 1

Participant demographics

Participant role	Gender	Race	Education level	Language
ESDM Therapists	Female (3)	Black African (1) White (2)	Tertiary	All English & Afrikaans - Xhosa, Zulu, Sotho (1)
ECD Supervisors	Female (2)	White	Tertiary	English & Afrikaans
ECD Workers	Female (2)	Black African (1) Coloured (1)	Certificate	All English & Afrikaans - Xhosa (1)
Caregivers	Female (1) Male (1)	Coloured	Grade 12 (1) Tertiary (1)	English

Procedures

Two WCED schools were approached to participate in the study after permission was obtained from the Department, and informed consent was obtained from the ECD workers and supervisors. The early ASD intervention was then adapted into an ESDM-informed caregiver coaching intervention (see background above and Appendix A). Training of the ECD workers and supervisors in the intervention then took place, followed by implementation at the schools, and then participant interview by the researcher. The researcher set up individual appointments with each participant via telephonic and email communication. The researcher began by reintroducing herself, explaining the purpose of the study and framed the structure of the session. The researcher asked the participants to reflect on their overall experience of training in and implementing the ESDM; skills and concepts used and learnt; as well as their own knowledge of ASD. The participants were also told that the study was investigative, and were therefore asked to reflect on areas that they found easy and difficult and needing development pertaining to their training, their different roles as either an ECD worker, ECD supervisor, caregiver or ESDM therapist and the early intervention model itself for the current context.

Data Collection

Some methods and questions used in this study have been adapted from Curran et al. (2012), who conducted a similar multi-stakeholder qualitative evaluation for anxiety disorders that explored barriers and facilitators to intervention implementation. In this study, nine individual in-depth interviews took place after eight caregiver-coaching sessions, in order to allow for participant familiarity with the coaching materials and approach. The focus was on assessing participant experiences and perceptions of their involvement in the coaching intervention in order to identify barriers and facilitators to the intervention implementation. Semi-structured interviews were conducted in English with the ECD workers and their supervisors, ESDM therapists, and caregivers who were receiving the coaching. Open-ended questions enabled participants to provide detailed responses based on personal experience (Creswell, 2014), and the interviewer to ask clarifying questions. The interview guide, informed by a similar qualitative study used to assess the implementation of an adapted intervention for anxiety disorders (Curran et al., 2012), varied slightly based on the participant group. Four sets of interview questions were developed for each participant group (ESDM therapists, ECD workers, ECD supervisors, and caregivers). Questions asked included: *How did the therapy work in your school? How did the therapy affect your time commitments at home? How was ESDM received by those who worked with it in the schools, and how did that change over time? What worked and what didn't work? What outcomes did you see in the children you are working with?* (see Appendix C). All interviews were audio recorded and transcribed verbatim.

Data Analysis

Following transcription of all the interviews, data analysis was undertaken, informed by Braun and Clarke (2006) six-step thematic process of qualitative analysis. Thematic analysis is a flexible analysis method used in qualitative research to identify, categorise and describe the data in such a way that patterns of meaning can be drawn. Step one: Reading and re-reading all transcribed interviews. Step two: Hand-coding transcripts, a process which involved going through each line and assigning a code to the sentence or paragraph (Creswell, 2014). Step three: Identifying patterns, dividing them into categories, and labelling them according to themes. Step four: Reviewing themes under the broad categories of either a barrier or facilitator of implementation and sustainability of the caregiver-coaching intervention. Step five: Naming, defining and reorganising themes and sub-themes under each category. Step six: Final analysis of the data informed by the study aims, and represented in the results below. NVivo 12 computer software (QSR International Pty Ltd) was used to organise and store the coded data extracts under different themes and sub-themes, and direct participant quotes were added to illustrate these. The flexibility of thematic analysis allowed for the data to constantly be reviewed, while the rigour of the study was ensured through reflective journaling, peer debriefs, and member checking to ensure transcription accuracy.

Reflexivity

According to Denzin and Lincoln (1998), a qualitative enquiry is susceptible to researcher subjectivity, and so it requires the researcher to critically reflect on how they influence the study. A researcher's role, culture, class and personal background can also determine the values identified in the study and how themes are derived (Creswell, 2014), and theorists therefore encourage researchers to continue reflecting on their assumptions at different stages and levels of consciousness in the research process (Rae & Green, 2016). Rae and Green (2016) developed an adaptable reflexivity matrix that helps researchers question themselves at the pre-research, data collection and analysis stage of conducting a study.

My research interest is influenced by my background of working at a school for children with ASD and special needs. My daily experience of being with the children and working closely with them greatly impacted how I viewed and understood the disorder. The second influence came from my interaction with their parents and family members, who expressed appreciation for the support we were providing their child, but also shared their helplessness and frustrations. I am interested in finding out what interventions can be used and taught to parents to help them care for and support their children with ASD when the child is at home or not in a school setting. Such aspects were salient when I engaged with the participants and provided great insight into the study. My data interpretation is therefore informed by a number of factors, which include my studies on ASD; my brief experience of the intervention during the ECD worker training and implementation; the current knowledge on the needs of parents of children with disabilities; and more importantly from my understanding of the meaning made by the participants, which I report on.

Ethics

Ethical clearance for the larger study was obtained from the University of Cape Town Human Research Ethics Council (HREC) (HREC 039/2015) (Appendix D), in partnership with Duke University Institutional Review Board (IRB) (IRB Pro00064533) (Appendix E), and the Western Cape Education Department (Appendix F). Thesis ethical clearance was obtained from the Department of Psychology Research Ethics Committee (Appendix G). All ethical conditions for protecting human research participants were met. The researcher also completed the National Institute of Health (NIH) web-based training, the certificate is attached (Appendix H).

The purpose of the study and consent procedures were explained to participants, and written informed consent was obtained prior to data collection (Appendix I). Participants were informed that this was a voluntary exercise and that they could withdraw from the study at any time without prejudice. Participant anonymity and privacy were assured as no identifying data is included in the results, which reflect only aggregated data.

Chapter 4: Results

In this chapter, findings are presented from the individual interviews conducted with participants involved in the implementation of the South African-adapted ESDM-informed caregiver coaching. A summary table of results is available (see Appendix B). Themes and sub-themes are summarised and presented with representative quotes, and themes linked to the interview questions are integrated into the overall findings. The first section presents facilitators and barriers of the implementation of the early intervention. The second section presents facilitators and barriers to intervention sustainability in South Africa.

Implementation Facilitators

This section describes factors that facilitated the implementation of the South African-adapted caregiver-coaching intervention, including current ECD knowledge of working with children with ASD; perceptions around the experience of coaching caregivers; the usefulness of the "Help is in your hands" Community ESDM videos to demonstrate the intervention concepts; and the generalization of skills by participants to various child environments.

ECD worker ASD knowledge and experience

Participants described ECD worker baseline knowledge in ASD, and the additional skills they gained from coaching.

Baseline ASD knowledge

Some participants thought that it was necessary to include ECD workers with prior ASD knowledge and experience. However, it was noted that, with practice and support, ECD workers could learn coaching and intervention skills over time. One of the ECD supervisors believed that some foundational knowledge and experience in working with young children with ASD was important for an ECD worker to effectively coach parents in intervention strategies:

> *"If our ECD worker had more experience with autism learners if she had worked with us for 2 or 3 years and this training started now. I think she would be more comfortable if she actually knew more about autism."*

Although there was this concern around years of experience, one of the ECD workers noted that she had was learning as the implementation unfolded:

> *"I think I can use it. It is interesting and you learn a lot from the session. I've got more experience working with those children, you see. I think it is good for me. It did work."*

However, two of the certified therapists were of the opinion that a novice ECD worker was more amenable to learning new skills:

> *"I think because she's kind of newer to it. I think she's had training on the job I don't think she's had any other kind of formal training in autism. So, I think that's also kind of made it easier, and made her more receptive to information from us."*

> *"What I found most helpful and easier was that you didn't have to declutter, to get rid of stuff that she already knew, or ideas that she had about what she'd be doing with the child or what she'd be coaching with, it was much easier to work with her, because she just followed the script."*

Skills gained over time from training and coaching

The other ECD supervisor noted that, regardless of baseline ASD knowledge or experience, the more coaching practice that ECD workers had, the more comfortable they were coaching caregivers on intervention skills. Both ECD workers supported this sentiment:

> *"I think I can use it. It is interesting and you learn a lot from the session. I've got more experience working with those children, you see. I think it is good for me. It did work."*

> *"I've never engaged in something like this and I can actually see how I grew. I can actually see how I empowered this parent and through the parent, I can empower this learner. I think it's something very good."*

One of the ECD workers went further to reflect on how and what she learnt through seeing the caregiver implement the principles, "follow the child's lead," "imitate the child," and "praise the child," during coaching:

> *"I learn how to coach a parent. To teach his child what to do and follow his child's lead, and imitate what the child's doing, not tell the child but imitate and copy what the child is doing. And the other skill when the child is doing well praise the child. And the other skill after that, when he is doing the warm-up activities with the child, the child must do more and the Dad must do less."*

As the coaching progressed, the ESDM therapists observed an adjustment in the ECD workers, noting that, "It becomes more natural as they get more familiar with the intervention and just the structure of the sessions and everything."

Positive coaching experience

The sub-themes in this section represent participant perspectives about their coaching experience, having a session plan to provide coaching, and the importance of relationships when collaborating on a project.

In-session caregiver-coaching structure

Participants reported understanding their roles and expectations during coaching sessions. An ECD worker describes her role as a coach:

> *"My role is as a coach. I am just learning, just in that learning process. I have the coach that is coming to watch over me, supervise me, help me. My role actually is to empower the parent, so that the parent can help their child learn new skills. The parent goes back home and implements all of that, and then comes back to the sessions and I can see whether the parent took that information, took the skills and went back home and practised those skills with their child."*

The session plan, which systematically outlines the structure and content of each session in simple language, was found to be valuable by ECD workers and supervisors. One ECD supervisor explained that they knew what to expect because they had a session plan, which helped relieve anxiety and prepare those involved:

> *"I think the coaching session, the paper that they always give to the ECD worker with the questions, I could see that every week they were adapted just to make it easier for the person."*

The group of ESDM certified therapists shared the same sentiments:

> *"What worked was just repetition. Repetition of having a very clear structure, giving very clear instructions to the ECD worker as to what it was she needed to focus on, and then just sticking as closely to the content of the coaching structure that we could and I think that worked."*

Another of the ESDM therapists added that, "I think it's very helpful for them to be able to have the teaching points, to have it broken up in the way in which it's been broken up." They found that the ECD workers started to think in a more "ESDM manner" as the material and structure became familiar.

Value of team relationships

The ECD supervisors commented that the good relationships they had with the ESDM therapists created a platform for learning throughout the project. One supervisor noted:

> *"Well, what's working is the relationship between everybody. Everybody plays a very big role. I think we all also have a nice understanding and the attitude towards the ESDM model. I'll always ask questions, even the ESDM supervisors will always ask each other questions if they are unsure. The relationship amoung us is working. I think if we don't have a relationship amongst each other, and the trust to ask questions, not to feel stupid, we wouldn't be able to go forward. So then obviously in the sessions itself, we see more and more and more first-hand, how skills are just pulled off. "*

One of the ESDM therapists also mentioned this, noting that they had, "good enough relationships" which were "flexible" and allowed them to reflect on the coaching they were conducting with the ECD workers and their supervisors. Another supervisor commented:

> *"It's been really good. The coach like the ESDM therapists, they are very subtle when they coach the ECD worker to coach the mother. It's not in your face. It's very subtle, with maybe a touch or eye contact. And the ECD worker herself will look when she doesn't know the answer when mom asks her."*

The second ECD supervisor emphasised the value of relationship-building between the 'specialist' ESDM therapists and 'non-specialist' ECD workers. In addition, she noted the importance of keeping the ESDM therapist who supports the ECD worker consistent across sessions:

> *"Maybe if you could just use one person and just that person is the coach and you actually got a bond with that person. I think it's important to have a bond with one coach and, and you know when the person tap you, you know you have to go that side. The next week you got somebody else and her way is different from the other. I think it's important to just keep one person you work with for all sessions."*

Clear illustration of intervention concepts from the videos

Participants described their experience of the videos used to illustrate intervention topics in session.

Illustration of intervention skills

All participants found the videos "beneficial" to the implementation process, as the videos provided "visual" practical examples for caregivers and ECD workers. One ECD worker explained that the videos filled space in the session and that, when there were no videos to show, there was “a void.” She followed up by saying, “I wanted videos to be part of the session.” In another interview, one of the ECD supervisors said, “I don’t think we can do the coaching without the videos.” This was one of the most commonly reported facilitators of the caregiver-coaching implementation.

An ECD worker stated that the videos served as a refresher of the training she had received:

> *“The video is actually very beneficial. It’s a reminder for me of what I’ve learned in my training because I actually saw the videos while I was doing my training. And every Monday when I’m in my sessions and the mother’s watching those videos it’s a reminder for me what to do in the session and what to coach on.”*

The second ECD worker added her view of the videos in reference to her own personal life as a parent, both inside and outside of the coaching sessions:

> *“So what was my experience in the videos? This experience in the videos was more important to me, and it was very, very important because it shows you how to deal with your child. You see what you can teach your child to do and what goals you can teach your child to achieve at the end of the day and it give us more experience also.”*

Both ECD supervisors stated that the videos contained helpful examples of the session skill for caregivers:

> *“I like the way that every time they explained something, there was also always a practical way the parent can see how they teach the child the skill.”*

The videos also had a positive impact on the caregivers when they had watched the videos at home and saw it again during the session. This resulted in an increased understanding of the intervention skills by the caregiver, according to one of the supervisors:

> *“The mom inside here I can see she looks at that video. They go through the information. She watches the video and I actually think the video brings more understanding to the parent as well, because they see what they need to do. I think it gives you more confidence because you see a picture of what you supposed to do.”*

The ESDM therapists felt that the videos provided a simplified illustration of ESDM concepts for the ECD workers:

> *"I found the videos very helpful. I think the same thing for the ECD workers. I think it was very helpful for them to see somebody working with the child, and see what they were able to achieve."*
>
> *"I think what worked in the training was the fact that we had those videos. You could demonstrate with the videos and then practise the skill afterwards."*

The caregivers confirmed the observations of the specialist and non-specialist coaches. One remarked:

> *"What worked for me? The examples of parents doing the actual play, and the parts where you would read afterwards. That helped in understanding what the video was all about and what the play session was referring to."*

The other caregiver found that the videos helped their knowledge about how to teach social communication skills using joint activity routines. They were able to identify the concepts being taught from the visual representation in the video:

> *"When you play with your child you think some of it is just natural. The videos show you that when the child is interested in one thing, how to position yourself to be in the child's eye line to get his attention. I think that helped a lot."*
>
> *"After you go through the sessions and you see the results, you understand the video. Because sometimes I would look at the video and think: this person is just playing with the blocks, the mommy is just playing with him with the blocks. But when I watch the videos, I understand they're giving choices and the parents are allowing the child to take the lead."*

Mastery and generalisation of skills

Participants described facilitators that were related to mastery of the ESDM-informed caregiver-coaching skills, and generalisation of these skills to various child environments.

Skills mastery by ECD workers and ECD supervisors

ECD workers and ECD supervisors reported applying intervention skills in different settings. One ECD worker could see herself coaching in her ECD classroom and her community:

> *"Definitely this is something that I can take into my class. And this is definitely something that I can do in my community. If there's a child that I can see, this is where the need is, this is definitely something that I will be able to use and want to use when the need is there."*

The second ECD worker applied the intervention techniques in her classroom:

> *"From that four-day training goals that we were using there, the pointing, I do implement it in the class with a child I have. I try to teach him trying to point when he wants something and it does work for me."*

She also described how she had applied the skills in her home and found it beneficial:

> *"I learn more how to deal with my child when I'm at home when during playtime, bedtime, mealtime."*

ECD supervisors shared similar experiences when they used intervention skills with their class. One explained that she realised she was using the principle of, "stay in the spotlight" unknowingly:

> *"I think it's very interesting. I actually also learn a lot because just for my own person, because I'm working at the pre-school phase then when I see that there's making eye contact, I will take what I actually learn by the training I think just to go to see in the class. See if we can maybe stay in the spotlight, that's more stuff that you actually do without recognising."*

Intervention skill mastery by caregivers

Caregivers generalised and structured the techniques into their daily routines. Below, one caregiver described how she applied two intervention skills, of "letting the child take the lead" and "imitation":

> *"The videos help to see what type of play you can use. In the one play, they use peek-a-boo. On one occasion, my child does yoga at his school, and he will do these*

> *actions. I was like okay, this is a perfect opportunity to just mimic what he's doing, for him to take the lead. We had this moment when I was just copying what he was doing. But it was also because of the videos. You can practically see how you let the child take the lead."*

The caregiver commented on her subsequent awareness of her child's behaviours and interests in creative play, something which previously was not so apparent to her:

> *"Outside there were leaves that fell off the tree. Then he gathered the leaves and he took a stick and he making a fire. It was so good because, during the coaching sessions, I didn't as a mom understand how important imaginary play is. How important it is for the development of a child. I never understood the magnitude of it and how important it is for you as the parent to go inside their world and join their imaginary world."*

The other caregiver shared his experience of his child learning through colour naming play, and noted that the activity did not take time out of their day:

> *"When we walk there's a big ToysRUs sign. The ToysRUs sign is red, orange, green, blue. That's the way we taught him colours. Every day we walk past it, I go "red", now he goes "red", and now I go "yellow", he goes "yellow", "blue" and there's another "blue". That's the way we taught him. It didn't take any time because we walk past it every day, all the time."*

The caregivers also felt that intervention skills were applicable to their other children, as they realised how children learn from their environment. One said:

> *"I have an older child who's, you can't say normal, but he's not autistic. You can even implement these skills with them, to teach them things and to show how much children pick up from their parents and from other people."*

Implementation Barriers

This section describes the barriers to the implementation of the caregiver-coaching intervention, including participants' perspectives of the intervention and coaching concepts, the logistical challenges faced by the ECD non-specialists, and the misalignment of the video content with the South African context.

Intervention and coaching concepts

Participants described challenges related to the complexity of the intervention and coaching concepts, particularly in relation to how these differed from the traditional ECD worker education received at training institutions.

Complexity of concepts

All the participants expressed some difficulty with understanding intervention concepts because of the language used, describing some terms as "jargon":

> *"Sometimes the language. I think some of the language that got used sometimes has a fair bit of jargon in it still, and I am not always sure if the parents could always relate to that."*

This became apparent when caregivers stated that they needed more detailed explanations of the purpose of the session skill in order for them to fully understand what was being taught:

> *"Because I like to know why you understand? I don't always understand why. I think we all do things differently and sometimes when someone knows why something happens then we can better understand what it's about."*
>
> *"Sometimes like toy play is different to mealtime so you know that the person as a professional, you know how therapy works or what the end result is, you've got the theoretical knowledge of what needs to take place. So as a parent with not having that knowledge sometimes we not sure what the point of the play is."*

This sentiment was echoed by one of the supervisors, who reported that the coaching required a "mind shift" from the caregiver and that the purpose of the strategies that caregivers were being coached in needed to be explained to them more thoroughly:

> *"The latest session was quite difficult with the parent, and it wasn't really the child. It was more the parent, to make that mind shift because we were focusing on teaching the child to point, but the boy was taking his parent's hand to point. So it was difficult to go into depth because the parent, he knows what we say, well actually what they say but sometimes I feel like the parent doesn't understand what he must do."*

The need for a caregiver "mind shift" was also noted by the ESDM therapists, who perceived that this would result in caregiver behaviour change during their interaction with the child.

They noted that the intervention concepts were somewhat difficult for non- specialists unfamiliar with this approach to understand:

> *"So, I think that really understanding their role was something that was just more a difficult concept to put across."*

This notion also seemed to imply a need for the ESDM therapists to spend more time conveying the information more clearly. One of the ECD workers reflected on the pressure she felt at the time:

> *I have this expectation and how am I gonna do this now. Because when I look at the other coaches, these therapists when I look at them, the way that they talk to children and the way that they express themselves with these nice voices. It took me a very, very, very long time to get into my own skin and to find myself because I actually see that this different persona that I want to put up or I got this imagination in my head that is how it's supposed to be done it didn't work for me.*

Furthermore, the therapists indicated that the ECD workers' primary language, which may not be English, may be a barrier during coaching, because the intervention concepts were communicated in English videos. This may have impacted ECD workers' performance and caregivers understanding of the intervention content, as shown in the quotes below:

> *"It was a big mind shift for the ECD workers, especially for the ECD worker with more experience because she's used to doing things in a particular way. In South Africa, if you're a teacher you give an instruction, you instruct the kiddoes to do what you tell them to do. So I think they were surprised by a whole lot of things that we didn't seem as focused on, for example, teaching kids shapes and colours."*

> *"I think sometimes just being careful of some of the language. Like a joint activity routine even though it's really nicely explained and set up, as a professional it's much easier for me to understand, so I don't even really question it. I just hear it and I know what it refers to. I'm not always sure as a parent whether it would be that simple for them."*

Misalignment of ECD worker training with a caregiver coaching approach

The differences described in the quote above were not the only ones identified. The didactic approach which ECD workers are accustomed to, as opposed to a collaborative approach to teaching children and their caregivers was seen as a big challenge:

> *"I think what was a challenge, is for the ECD workers to understand their roles, to understand that they're not going to be working with the child."*

Participants noted differences between the coaching by the ESDM therapists and the ECD worker training, which contributed to anxieties about doing the coaching themselves. One ECD worker described her experience this way:

> *"With the training, I had a lot of anxiety because I actually thought with learning this, now we must go and implement it and I really just had in my mind, the way the therapists are talking to children, with this soft voice. I think that was the biggest fear, how am I going to express myself in my own voice, and in my own body? I thought I had to take on a different persona to make this work."*

The perceived lack of expertise in intervention concepts and coaching was reported to have affected how the ECD worker performed, with the above quote implying that her confidence was affected as a result of her inability to understand and express concepts in her own way.

The certified ESDM therapists reported that the caregiver-coaching concept of "reflection", where caregivers are encouraged to link behavioural strategies that they used to social communication behaviours they saw their child demonstrate, was one that was particularly difficult for the ECD workers to grasp, as shown in the quote below:

> *"When we say to the ECD worker, they must reflect, as a psychologist I know what reflection is, so I ask the question: what did you see? I can also do follow up. I don't have to follow a script. I can listen and do that. I think for other people it's a new concept."*

The process of learning new intervention concepts and taking on the new role of the coach was described as "a huge transformation" by one ECD worker, with all participants agreeing that it required changes to how ECD workers engage with the caregiver-child dyad. The certified therapists felt they needed more time to train ECD workers, who would assume the role of "caregiver coach" as opposed to "child teacher". One therapist added that:

> *"So I think with the training maybe we need to, we needed to spend more time, and I am not sure how that would work. I don't know if these guys could take time out of school for more than the week that they did, but maybe it's just something to think about how do we make more space because I do think these concepts are difficult."*

The certified ESDM therapists felt that there was a need for longer training sessions, due to the concepts being difficult to teach. This was supported by one of the ECD workers, but this thought was mainly restricted to the group of certified ESDM therapists. Recommended changes were more practise with the ECD worker in the role of the parent, and a longer initial ECD worker training, as shown in the quotes from the ESDM therapists below:

> *"I think the only change that I would make would be to do two or three sessions with the ECD worker in the role of the parent."*
>
> *"I think really understanding their role was something that didn't work well with the training. It was a difficult concept to put across. I think after the first two days of training they were only starting to understand it, to get it. So it took a bit longer."*
>
> *"I do think around the reflection, and picking up on cues from the parents, and how to balance sticking to a 'script' and listening to what parents say. It doesn't have to be complicated, you can just practise a little bit more perhaps."*

The certified therapists were all of the opinion that the ECD workers would improve and become more confident through practising skills like "reflection." Another therapist provided further insight:

> *"I just think it may really be helpful for them to just have some first-hand experience of what it's like trying to get a child's attention, trying to set up a routine, trying to elaborate on a routine and how to close it down. I just think there's a sense of having actually done it themselves, some of the coaching may then just be more intuitive and more instinctive for them."*

An ECD worker commented on challenges related to the skill of reflection:

> *"The beginning was very difficult for me because when it gets to where we have to do reflections with the parent, sometimes the parent…because there's so many things happening in that moment… that the parent couldn't remember what the child did or I couldn't remember."*

Logistical challenges

The following sub-themes outline the logistical challenges faced by participants that are relevant to intervention implementation in their setting and include: a lack of time, and scarcity of physical resources for caregiver-coaching.

Time constraints

The coaching sessions took place during school hours. Both ECD workers and one ECD supervisor reported feeling pressured for time between managing their classrooms and preparing for the coaching sessions. One ECD worker noted:

> *"If I was having more time to look after the session, to prepare for myself. I didn't, I don't want to lie, I didn't prepare. If I had more time then it will be. I've got my work to do on the other side, and I've got this."*

The second ECD worker was soon able to adjust, and fitting the coaching into her schedule "became a norm." A similar situation arose with the ECD supervisors, where one felt that there was no added pressure to her schedule or workload, whilst the other supervisor described her experience as being "difficult":

> *"It was a bit difficult because you teach. I have got my own class and I'm actually at the pre-school phase so, they are very busy. I think there is a lot of potential with the sessions. I think it can work, but it's difficult for us to get out of the class and you still have kids with you."*

The group of certified ESDM therapists noted that the coaching put some strain on the ECD workers and their supervisors.

> *"The Head of Department of the ECD worker had to take time out of their schedule in order to be there. I would imagine that they were having to, at minimum, give an hour and a half per week to us."*

However, the therapists noted that the ECD workers and their supervisors seemed to manage the additional caregiver-coaching responsibilities.

> *"There must be an effect because it's teachers or ECD workers who would be teaching and they are taking time out of their day. I know they are trying to organise other people to fill in for them. But it didn't seem like it is not doable or it is too much of a burden for them. It seemed manageable and they have always been able to come up with suggestions. I think they're adaptable."*

Access to physical resources: dedicated coaching space, computer and internet access

Different views were reported at the schools regarding the size or absence of a dedicated coaching space. Two ESDM therapists stated:

> *"I know that at X school, the school was being painted in the last two weeks, so the space was being used twice over. A class had to vacate in order for us to be able to go into the space. They had to move equipment."*

> *"What might impact at X school is the space that we have to work in. I think it's a storage room and in last week's preparation they had to move out stuff."*

The ECD supervisor at this school felt that the space required improvement:

> *"I would love if we had the money to have a nice big room where we had a proper mirror. But this is working at the moment. This small space that they are actually in. We have a baby monitor. We have got it all. I wouldn't mind having a bigger space, with a legit two-way mirror with sound, you know, proper things."*

While space was not a major concern, other logistical issues acted as implementation barriers, such as access to a dedicated laptop to show the caregiver "Help is in your hands" videos, and lack of reliable internet access (although this was not required to play the video material). One therapist reflected on this:

> *"The buffering and more logistical stuff with us having to work with that, it takes forever and there is not enough bandwidth and technical issues."*

Adding to this, another ESDM therapist commented that, “They had to get a computer, so there was sort of that practical stuff that took time.”

Video Content misaligned with South African context

One of the issues identified as a potential barrier was the lack of applicability of the video content to the diverse South African environment, and the need for material that is locally-produced.

Mismatch of material with South African context

Participants noted the mismatch of the “Help is in your hands” videos used in the coaching, with an ECD worker describing her experience:

> *“In the beginning when I was in the training, I had thoughts that these are not our communities, that is not how our communities operate, and those are not the type of homes that our kids are coming from.”*

Similar sentiments were expressed by the certified therapists:

> *“I think if I was a parent coming in, and I was watching it for the first time, I may not expect that it’s going to be American.”*

Other barriers referenced the impression the house and toys in the video may have left on the parents, with one therapist explaining:

> *“I think it’s not nice to show parents something that they can’t afford. Because they start thinking oh, I need to have that in order to be able to do this. When in fact, the material or the objects in themselves are not the primary things. They are a means to an end. They are not an end. Parents start thinking: “I need to have this; I need to have this, and I need to buy this toy.” As if the toy itself is what will get the kiddo to reorient. Actually, we want them to move their attention from the toy to the person.”*

A key aspect of the problem was expressed by one of the ECD supervisors, who noted that she did not want caregivers to think they needed to have “this room, lounge or TV room” to use the skills at home. Another therapist remarked that, “They illustrate the principles very well. I just think they [the video content] are a bit foreign.”

However, even though the videos were developed in the U.S., an ECD worker noted that they still achieved their purpose:

> *"But I can now see that even though our children do not come from those homes, when they are in the room, it is still the same. They still learn in the room and in the session what they supposed to learn."*

Interestingly, caregivers' perceptions of the video content were somewhat different from those reported by other participants. Caregivers did not provide a clear indication that U.S.-based video content was problematic:

> *"But generally it doesn't matter whether it's in the USA or whatever; kids are all the same."*

> *"Whenever you switch on the TV there's only Americans anyway."*

However, the language was seen as a potential barrier for other caregivers who may not understand or speak English. An ECD supervisor commented:

> *"We have parents in our school that don't understand English. That is an actual barrier to their understanding of their child's diagnosis and what we are doing in the school."*

One caregiver added that their child was older at diagnosis than children in the videos, and this affected his ability to relate to some of the material presented in the coaching:

> *"I think the only thing was that my child was diagnosed when he was a little bit older probably, so I don't even know if those children are autistic or not."*

The ECD workers, ECD Supervisors and certified ESDM therapists all indicated that South African videos, with local families and children, would be of great value. One therapist noted:

> *"I'd like to see us develop our own materials because I think that's going to be more useful. So not all kids have those little stoves and kitchens, and those expensive toys. Not every kid has that. Maybe we just need to be able to develop materials and get parents to work with things that they can. A lot of the kids like bubbles and just simple things. Like things that are available locally and the parents already have."*

With reference to the concern around language and there being an “accent” in the videos, one ECD supervisor shared her recommendation:

> *“We could reach more people if we talk the language of the country. Because even if you go to Spain or wherever they may be some who don’t understand English that well? Maybe English and Xhosa is not a bad idea if you want to target South Africans.”*

These varying perceptions resulted in one major suggestion for improvement of the videos: *Creating South African videos with local materials and include South African languages.*

Facilitators to Sustain the Intervention

This section describes the factors that would contribute to sustaining the adapted caregiver coaching intervention in the schools where they were piloted. These factors include significant improvement in child social communication skills and caregiver sense of competence as a result of the coaching intervention, as well as structural factors promoting intervention sustainability. The section also outlines an aspect of caregiver advocacy for the continuation of the project in order to reach more families in need of therapeutic services.

Child and caregiver outcomes

Participants were optimistic about child social communication outcomes, caregiver engagement in the coaching process, and increased caregiver sense of competence as they mastered intervention skills.

Child outcomes

Significant clinical changes were observed by all study participants in the two children who received 12 intervention sessions. Caregivers indicated improvements in their child's expressive language abilities:

> *“I think his speech has improved tremendously. I think he’s probably up to more than a hundred, 200 words, 4-word sentences. Not all the time but can ask for pretty much anything he needs.”*

In the quotes below, the caregiver commented on using the concepts of "one word up" and "labelling" with words the objects and actions used in routine activities, such as dressing, and mealtime. These helped his son develop receptive and expressive language.

> *"So everything he does, you say, and at a later stage, he'll start saying it. My child is at a stage where he's saying "puts on pants", "put on shirt", "drink tea". He's doing now the same thing, but not just labelling it. He's saying what he's doing on his own."*

> *"I think definitely the 'word up'. Using one more word than what he's saying. That's the one, and then labelling everything he does. That really helps him. In the beginning of the sessions, I said I mainly want him to be able to speak properly. Those two things have definitely helped a lot. Just teaching him while playing every act, everything he does we try to label. When he's putting on his pants when he's eating food, "you are doing this", "you are doing that". We keep adding. When he says something, we keep adding a word. Repeating, repeat all the time, that has really helped."*

Previous attempts by the family left them feeling frustrated with the child's repetitive use of language and related behaviours, but this had improved since learning intervention skills:

> *"Before, it was difficult to realise what he likes and what he doesn't like, and how he responds to it. We would also get frustrated with the repetitiveness of some things. Now we sort of accept the repetitiveness of some things and add something onto that. So that it's firstly for him, he learns something, and also for us to remain sane. He would repeat things over and over and over. Now instead of just repeating after him, we add something to it. So that helps. It's just to understand him more."*

The other caregiver found that her child was showing affection towards his siblings, and attributed this to the intervention techniques and coaching she received:

> *"Overall, his communication has improved, his affection, we will come fetch him at school, me and his two sisters and then he will hug them, and that's a good thing. Before he would say "mommy", but now he will be happy to see us and he'll hug his sisters."*

The child was having “fewer meltdowns,” and his behaviour had become easier and “more manageable”. She also observed that he had begun to play with his siblings. She commented, “I find that he still keeps his distance but he will engage with his sister, he will engage in her imaginary play as well.”

The other caregiver also mentioned that his child had started inviting him into his play:

> *“There’s a lot of routine. I think he has like a built-in clock anyway. So when it’s time to do these things, he’ll bring it out himself and start doing that, and he wants me to draw something or build a puzzle with him he’ll do that himself and just call me. And sometimes he’ll do it on his own as well and I let him do that. He’ll, for instance, he really likes to draw. I think one of the therapists probably knows he always draws. And he draws a man and a pig and ball. And he’ll call me, he says Dada, draw a man. And then I take his hand and we together draw a man. It’s a very basic man, but it’s still a man. Or a pig, he‘ll say, Dada, draw a pig. And then we are trying to teach him how to write his name. He’ll say draw X, that means he wants to write his name. So he’ll definitely label the activity and call you.”*

The ECD supervisors stated that they had seen “a lot” of clinical changes in the children who received intervention, conveying this sentiment below:

> *“The outcomes? Oh, a lot. I’ve seen the boy talking more, saying single words more, requesting, also verbalising his frustrations, “no” or “help”, “don’t want”, requesting what he wants, making choices, playing with mom, making eye contact with mom, inviting mom to play along. There’s a lot. If I look at the first session, and I look at the session we had on Monday, there’s such a big difference in how he’s actually starting to use phrases, turn taking, sharing. I think the important thing is interacting with mom. He’s not turning his back to his mom anymore. He’s more aware of her and wants her to play along with him. So those are the outcomes that are very important for our children that I’ve seen. And I’ve seen it first-hand. It’s amazing.”*

The ECD workers echoed similar reflections about child clinical outcomes:

> *“He is a child that’s non-verbal, but he makes sounds. I could see he’s starting to pick up words. I can see even sentences, one sentence, one full sentence. He’s gesturing*

> *with his whole body, and he's using his body, and he makes eye contact with his mother. He really express his needs. When he got here, in the beginning, we had to teach him how to express his needs, how to use his body, how to gesture, how to make eye contact and not to cry for what he wants. In the sessions, he also learned about making choices. I can actually see slowly but surely how these sessions are helping him to become independent. Although his mother is there to assist him in every other thing. It's like he's just growing, or he's just developing all of these skills through these sessions."*

The ESDM therapists could see the clinical progress that the child was making, and noted that caregiver-child engagement in activities was lasting longer during intervention sessions:

> *"I think what we've been able to see is more language, you definitely hear more language, more vocabulary from him. I also think being able to stay in activities for longer. That and definitely more communicative intent with his father."*

Similarly, another therapist noted increased engagement during play, and an awareness of this by the caregiver:

> *"In the one kid, a big change in his ability to stay in the activity for longer, so he can expand the kid's attention. Also, it's been nice to see the kid sit there with the Dad and play, and the interaction between them. But more than that, it's seeing the change in the parent, almost like a change in smiles and how they interact with the kid. I think it's just a pleasant surprise for the parent to think "my kid can do this", so there can be fun here. That's the other thing, I see a mind shift that learning can be fun, and should be fun because it's how kiddoes learn."*

Caregiver 'buy-in'

The group of certified ESDM therapists indicated that the caregivers were "very invested and I think committed", as well as "engaged" during coaching:

> *"I just know that the Dad is really committed to it, and is very keen to keep on coming. He watches all the videos and he comes back and he's got questions, which means that he is thinking about things and is processing it. The feedback from him therefore, if I interpret his behaviour, seems very positive."*

This statement was reiterated by one of the ECD workers, who said:

> *"It's helped a lot because the parent when he is finished the coaching session when he goes home, we also give him the activities and a refrigerator lists so what he can implement when he's at home. It works quite well. Dad also sees that there is also an improvement."*

An ECD supervisor noted that the mother was:

> *"Doing her bit, she's understanding the skills very well, making it her own, practising at home. We are seeing the progress in the child. We are seeing mom's confidence growing."*

One caregiver described his experience of the coaching as only requiring:

> *"A little bit of effort most of the time, not really time, it's a slight adjustment in the way you, not even teach, but play with your child."*

The other caregiver noted factors that maintained her interest in the coaching. These included an increase in her child's interaction at home, and how coaching benefited her whole family. She also added that the refrigerator lists helped her work out a system at home:

> *"It works. It works and it's just a brilliant project. I sometimes I hear about other moms that have autistic children and I wish they could just go on this programme. Just know how to play with their kids. Especially when they are little. When the results are so positive after you've gone through the sessions."*

In further discussions about the impact of time and the application of skills at home, one caregiver noted:

> *"Because the therapy is much about everyday life, it doesn't really affect your time commitment that much. I mean we incorporate when he gets dressed, brushes his teeth, puts on his shoes, plays outside."*

Their buy-in had much to do with their experiences of finding interventions for special needs children in South Africa:

> *"My child did go for speech therapy once a month, and it's not really enough. When you get to do it yourself, I'm not a speech therapist and surely there's not one*

> *therapist for every autistic child or child who is in need? So if you can help your child in any way, it's very positive"*

The caregivers expressed "hope" that caregiver coaching would continue and go:

> *"...from strength to strength and that it becomes a reality in South Africa, all over the world, in all the countries, because it's really something good that can benefit special needs children and other kids as well."*

Caregiver competence

In the descriptions below, caregivers described feeling a greater sense of competency parenting their children as a result of the intervention. One of them reported that in the past she did not know when her child wanted something to eat:

> *"I would anticipate when he's hungry... But now you just have to listen also because sometimes he just says one word and you understand."*

> *"It's given me confidence to say I can do it, I can help my son. Sometimes parents feel alone and they don't know what they can do for their child."*

> *"The challenging part of having a special needs child is that you are not in control. You know they have challenges which are not easily overcome. When you as a parent don't know how to help them overcome their challenges, that makes you feel helpless. So, when you've been given a tool to help them help themselves, you feel empowered."*

The ECD workers described how the skills helped support caregivers in caring for their young children with ASD:

> *"This coaching session is very good because some of the parents don't know how to deal with their children. Some of them lose hope. Some of them are frustrated. Some of the children are not verbal, there is no communication. If they can come to this session, at least they will know how to deal with their children."*

One ECD supervisor added: "I think this training boosts them because I think sometimes parents think, "I'm not the expert" and "I can't do it."

Structural factors promoting intervention sustainability

ECD workers and supervisors described the significance of and need for ongoing live supervision from the ESDM therapists, and the feasibility of embedding the ESDM-informed teaching principles into an already-existing school system.

Need for ongoing live supervision

An ECD supervisor commented on the benefits of sustaining a caregiver coaching intervention that supported the development of social communication abilities in young children with ASD for the education system of South Africa:

> *"Many people want reading to happen, they want counting to happen. But before all of that, we need joint attention, we need eye contact, we need choice making, turn taking, interacting with your peers, with your environment, understanding where you, requesting. If we can lay down all of those skills and teach that to the child, and he comes in or she comes into our school and is ready to learn, then how amazing would that be?"*

However, in order to sustain the caregiver coaching intervention, ongoing supervision and support would be required, as an ESDM therapist explained:

> *"As we go along and the ECD workers develop more skills, they'll probably need fewer of us there but I don't think we should let them at this point work on their own without live supervision. Because I think live supervision is quite important for this. The live supervision I think should continue for, for quite a bit."*

On the prospect of there not being any supervisory support, one ECD supervisor commented:

> *"Are we not gonna have any support? We will continue using the therapy when the study is over, but I'm just scared that the model won't be implemented correctly. I will fight for it. My ECD worker will fight for it because she's been taught these skills and it will go to real waste if you don't use it."*

The following quote from an ECD worker describes the experience of live supervision:

> *"The team really support me where I need the support. Even with my supervisor, the support is there and I don't think I would have been where I'm at if it wasn't for the*

> *support that I'm getting from her as my supervisor and the ESDM team of coaches. The communication that we have, they're really trying every week to break it down and make it as simple as possible for me so I can understand what I'm supposed to coach on, what is important and what I'm supposed to do."*

The ECD workers described how being trained in intervention concepts, practising intervention skills with a caregiver-child dyad during the training, and then coaching caregivers in intervention skills helped to teach them strategies to work with children with ASD, in addition to teaching them how to better support caregivers. One of the ECD workers believed that, "just consistency" and "feedback" from the certified ESDM therapists supported her in her role as a trainee caregiver coach:

> *"I am just really excited to see how far I can take this. I am just really excited to see if I can grow more. The thought popped into my head the other day. I would just like long-term to be in a position where I can coach alone. So that is my long-term goal because I'm not there yet."*

Feasibility within the school system

In addition to ongoing supervision, if the caregiver coaching was to be sustained, system-level factors would need to be considered, such as workload and finances. Considering the factors that may act as a barrier to sustaining the intervention, one ESDM therapist reflected:

> *"I can see how it can work with one child, but if you want more than one child you know, to almost give them a bigger load. I do wonder how it's going to happen if they already have a relatively full, full day? I think it's a time thing, and time equals money."*

Along with this, another ESDM therapist felt that the extra workload could be alleviated by having a full-time caregiver-coach:

> *"Probably it could be sustainable if the school kind of then has someone, so for example if the coaches that we are working with freed from other duties so they can coach different parents. So it can be sustainable in that way because at the moment, they do that in addition to other tasks that they do."*

An illustration of this extra workload can be seen in the quote from one ECD worker, providing some insight into her duties:

> *"Yes, it does affect, because most of the time when I was doing the session it was half past 9 o'clock or half past 9. I'm not quite sure about the time now but I have to leave my children to the assistants and come and do the session. I mean it's serious, it's not fair you see because I have to be there for my children."*

In a previous quote noted again below, the ECD supervisors highlighted issues that were key to sustaining the intervention, alluding to a need for financial assistance for the project:

> *"I would love if we had the money to have a nice big room where we had a proper mirror. But this is working at the moment. This small space that they are actually in. We have a baby monitor. We have got it all. I wouldn't mind having a bigger space, with a legit two-way mirror with sound, you know, proper things."*

One of the ECD supervisors was also enthusiastic about being trained as a 'coach' and learning skills that would help them work with children at the school. She said, "I would love to also be trained, but I know it's also money."

It also became apparent that other teachers were also curious and willing to learn about the intervention:

> *"In the junior phase, there are at least three teachers that would love to know more. We are seven in total and they've been asking a lot. What do you do? Especially after the training, they still ask are you doing ESDM still? What is ESDM strategies? They are still interested. They are very much interested*."

The other ECD supervisor felt that, to sustain the intervention, it would be necessary to match the caregiver coaching with parts of the school most closely-aligned with providing support and outreach to caregivers:

> *"I actually said to one of the therapists, if we can continue it next year we can take a child, so that's where I think I would move a bit back. And because I think the main focus would be rather on X because she's working with the home programme. I think she doesn't have a class, she has appointments one to one."*

One of the ESDM therapists expressed a similar sentiment:

> *"I don't know of the other school, I do know that they have some kind of programme where parents come in. So it would be sustainable if we can find a way to slot into those. In other words, to work with what's already there and make adaptations or adjustments to that, so that it's not an added thing. So it would work if we didn't have to add or change anything, but if we are able to get the school to think ESDM principles in engaging with kids, especially the pre-schoolers that come in as well, the ones in the ECD classes. If there's any change in terms of the theoretical framework or understanding of how to work with the children then yes, it will be sustainable. They are all excited, and they see the change in the kid that we work with."*

The therapists' suggestion seemed to mirror those of the ECD supervisors, that the intervention principles should be practised and utilised within the existing school curriculum:

> *"I always say it would be great if we could all use ESDM strategies in, as a teacher in your class with a group."*

Barriers to Sustaining the Intervention

This section describes barriers to sustain the caregiver coaching intervention, including structural issues of poverty, lack of reliable transport, and unemployment.

Structural issues

This sub-theme reflects on the socio-economic difficulties for families with a child with ASD, and the plight of being poor and unemployed in South Africa.

Poverty, transportation, unemployment

One caregiver-child dyad withdrew from the study after the baseline assessment and three coaching intervention sessions, but unfortunately no individual interview could be set up with this parent to explore her experience. One ESDM therapist described this early barrier:

> *"And what didn't work? I think it is the intrusion of reality. The contextual factors. People are poor, and there is not great transport. We thought about them, and we knew that it's a thing we have to consider."*

Reflecting on the accessibility of therapeutic services, the therapist added that,

> *"The one child can come because the father is not employed. I also think they probably have a bit more resources than this other family. So the lesson to learn here, is for us to really think how we are going to work with these families in South Africa?"*

The ECD worker involved in this implementation explained how this was something familiar for them:

> *"The children that are at our school, they actually come from a very low socio-economic, poverty-stricken families."*

When a caregiver found employment during intervention sessions, scheduling for the sessions had to be changed to accommodate the caregiver. Although the supervisor reported that, "We were very adaptable because the father started to work again", the changes affected the ECD worker's schedule:

> *"It's very difficult for me because we do it after school hours, so it's very difficult. But okay, we just want to also accommodate the father because we nearly finished with the 12 sessions. So I will be okay till I finish that session. But Friday it's a bit awkward for me. And the other thing now is doing the session and being in class with the children it's also difficult, you see?"*

Chapter 5: Discussion

This qualitative process evaluation sought to understand the barriers and facilitators to implementing and sustaining an evidence-based caregiver-coaching early ASD intervention, delivered by non-specialist ECD workers in South Africa. Nine participants were interviewed and thematic analysis yielded themes and sub-themes.

Implementation facilitators included: ECD worker baseline ASD knowledge and experience and, skills gained over time from training and coaching; positive coaching experience and an in-session caregiver-coaching structure; the value of team relationships; clear illustration of intervention concepts from the videos; and mastery and generalisation of intervention skills by all non-specialists. Implementation barriers included: the complexity of intervention and coaching concepts; logistical challenges and; video content misalignment with the South African context. Facilitators to sustain the intervention included: child and caregiver outcomes, caregiver ‘buy-in;’ and competence; the need for ongoing live supervision and feasibility of intervention within the school system. Barriers to sustaining the intervention included: structural issues of poverty, transportation and unemployment.

Findings suggested that regardless of baseline ASD knowledge amongst ECD workers, coaching skills could be gained over time with ongoing supervision and a clear session structure. Caregivers, ECD workers and their direct supervisors experienced a positive coaching experience, which they related to the in-session caregiver-coaching structure as well as strong team relationships. The partnerships between non-specialists and specialists, in addition to support from the ECD workers supervisors facilitated learning of unfamiliar methods of working and materials. Previous research had also found positive results arising from knowledge-sharing and supervision from specialists to non-specialists (Rahman et al., 2016; Reichow et al., 2013).

The inclusion of “Help is in your hands” ESDM videos and materials was a positive procedural facilitator. Participants felt that the videos clearly demonstrated the intervention concepts. Previous implementation research that made use of videos to demonstrate skills found that it simplified the learning experience of the participants (Blake et al., 2017; Parsons, Cordier, Vaz, & Lee, 2017; Tilahun et al., 2017), and while the videos in this intervention were not tailored to the South African context, they appeared to achieve their purpose for this group of participants. As suggested, this may be because the majority of the participants were familiar with U.S. culture and the English language, but this may be problematic for people without such exposure or proficiency in the English. A significant study finding was caregiver and ECD worker report of mastery and generalisation of intervention skills. For the ECD workers, this suggested that the training and supervision structure was effective in supporting intervention skill acquisition. For caregivers this suggests that the intervention enabled them to integrate intervention techniques into their daily routines. Moreover, suggesting skill repetition and maintenance over time by the caregiver, positively impacting the child through extended learning across other settings.

Barriers affecting implementation were also shared across the stakeholders. Notably, some of these barriers were reported either in one participant group (for example, only from the ECD workers), or were only experienced at the beginning of the implementation process but were no longer considered salient barriers by the end of intervention implementation. The first included difficulty in understanding some of the intervention concepts at the start of the project, with participants reporting that the concepts were complex. Importantly, the use of videos to illustrate the intervention skill seemed to alleviate some of these difficulties. Second was concern regarding misalignment of ECD worker training with a caregiver-coaching approach. As indicated above, this perceived implementation barrier was overcome when participants realized that ongoing supervision ensured coaching skills could be acquired by ECD workers.

Third, physical space for intervention implementation was a concern reported at one of the schools, indicating that not all schools may be able to accommodate caregiver-coaching without financial support and appropriate facilities. This school did however manage to locate space where caregiver coaching occurred on a weekly basis. Lack of consistent internet access both at the schools where the coaching sessions were implemented and in caregiver homes is an important implementation barrier that emerged. The implementation team worked around this barrier by downloading “Help is in your hands” ESDM videos to school computers and providing caregivers with a flash drive with video material. However, poor access to data and internet in LMIC’s including South Africa is challenging for intervention implementation (Wetherston et al., 2017). This should be an important consideration when designing and implementing early ASD caregiver-coaching approaches.

The final implementation barrier was that some participants could not relate to aspects of the video content. Although the videos explained the concepts, the ECD workers, ECD supervisors and ESDM therapists expressed concerns about the characters only speaking in English and that the video content did not represent the local South African context. English is the third-most spoken home language in Cape Town and the Western Cape, and many households speak another home language (Statistics South Africa, 2012). This links to the longstanding suggestion to develop and adapt local material (Chambers et al., 2017). Future studies should consider the importance of culturally-adapting early interventions, to offset contextual issues arising from language differences (Cheremshynski et al., 2012; Guler et al., 2017; Harrison et al., 2016). This would require local financial investment. However, even with this perceived barrier, the video content was identified as contributing to improved participant caregiver-coaching knowledge and skill.

Factors were identified by participants that would promote sustainability of the caregiver-coaching approach. Significant improvements in child clinical outcomes were noted by all participants. Child clinical improvements noted by caregivers may have influenced continual parental commitment and "buy-in" to the coaching process, as well as continued interest and effort by ECD workers and their supervisors. The caregiver-coaching intervention also seemed to impact caregivers' sense of competence to support their child in developing new developmental skills. Whilst some literature suggests that caregivers may struggle to find time to practice the intervention skills (Drew et al., 2002; Ingersoll & Wainer, 2013; Pickard et al., 2016), in this caregivers reported that they were able to fit intervention skills into their daily family routines. On-going support of the ECD workers, in the form of supervision was noted by participants as a structural factor that promoted intervention sustainability. On-going support also minimised ECD worker anxiety and increased confidence. Live supervision provided consistent opportunities for intensive input, checking in and feedback. There was increased intervention understanding and competency by non-specialists. Potential challenges of implementing supervision for these types of interventions in LMIC's include local resource and time constraints, few trained specialists to provide training or supervisory support, and a lack of government aid (de Vries, 2016; Guler et al., 2017; Wannenburg & Van Niekerk, 2018). For this study, live supervision also ensured that the intervention skills were appropriately practised.

The final sustainability factor related to the need for increased institutional support for the intervention to ensure that caregiver-coaching could remain feasible within the school setting. While early intervention may align best with education department goals, there needs to be a shift in institutional support to make this happen because the educational Department does not typically provide services for children younger than 7 years. The focus is therefore on non-specialist Early Childhood Development workers employed by the Education Department to coach caregivers in early ASD intervention.

Barriers to sustaining a caregiver-coaching intervention included what was termed "the intrusion of reality." This is particularly relevant for this part of the world, where socio-economic factors impact upon caregivers' ability to access services. Early intervention in South Africa is very costly, inaccessible, and there is shortage of government support (Guler et al., 2017). These health disparities in South Africa are moreover quite evident in the failing social, political and health structures in implementing equitable policies, and providing healthcare services (Mayosi & Benatar, 2014). The impact of limited access to care is long term, preventing children from attaining their full potential.

Conclusion

This research sought to assess the feasibility of a caregiver-led early ASD intervention developed in a better-resourced country being implemented by non-specialists in low-resourced South Africa. It forms part of a larger pilot study of improving access to early interventions for ASD in Africa. The South African-adapted ESDM-informed caregiver-coaching was endorsed by all non-specialists, and these findings highlight several pertinent facilitators and barriers for discussion, the majority of which are facilitators of the implementation and sustainability of the intervention. However, the imperative for developing low-cost interventions in LMIC means that numerous adjustments and support have to be in place to sustain the projects. The results will inform tailoring of the intervention training and supervision approach for a larger pilot study. Positive child and caregiver outcomes could be offset by larger contextual and system-level issues such as poverty; and the need for ongoing support, supervision; and local coaching materials in South African languages.

Limitations and strengths

This was the first study conducted in Cape Town, South Africa, and it was limited in certain areas. Study limitations include the following: (1) The small sample size may affect the generalisability of findings for the other provinces, as the Western Cape is a well-resourced region (Statistics South Africa, 2017); (2) generalisability of findings for South Africa may also be affected because only two caregivers were part of the project; (3) as a pre-pilot study, the ESDM therapists formed part of the project team; (4) although some demographic representativeness was achieved, the participants were only recruited from urban areas in Cape Town; (5) no follow up interviews were conducted to ascertain whether the children maintained development or the caregivers maintained the skills learned; (6) it is unknown whether the caregivers transferred the skills to other family members; (7) the first caregiver recruited for the project withdrew after a few completed sessions. Ongoing implementation with larger samples can provide further evidence-based research for early ASD interventions in the wider context of South Africa, although contextual adaptations must be made.

To my knowledge, a notable strength is that this is the first study in Sub-Saharan Africa to investigate and find that the ESDM-influenced early intervention developed in a high-resource country is sustainable in an LMIC setting. As a pre-pilot project, it produced positive parent and child outcomes. It is also worth noting that the children who benefited are five years old and currently not in a special needs school, but on the waiting list. Lastly, the in-session live coaching meant that the therapist shadowed the ECD worker and provided instant correction and guidance about the coaching, thus contributing to confidence in the novice trainee ECD workers.

Implications for future research

This study highlights the feasibility of early ASD interventions as a strategy to overcome the bottlenecks that exist in countries with few services and human resources. Albeit the study is a preliminary step to providing cost-effective and sustainable early ASD interventions to families and those affected by ASD, it demonstrates that such interventions are applicable and adaptable in these contexts. Subsequent implementation should therefore replicate this with a larger sample. The fact that the caregivers in this study found the therapy fairly easy to implement suggests a positive impact on parent capabilities when they partner with professionals for caregiver-led programmes. The government and other health professionals should support tailoring early ASD interventions and caregiver-coaching initiatives, and the early detection and management of ASD. The recommendations made by the participants (see Appendix J) provide insight into the context in which the evidence-based research can be done. The study makes a significant contribution towards ASD research in SSA, highlighting non-specialist ASD knowledge gaps, the impact of knowledge gain, and indicating a willingness to learn about the disorder and how to manage it. Future research should evaluate the uptake of ESDM-informed caregiver-coaching from a larger sample.

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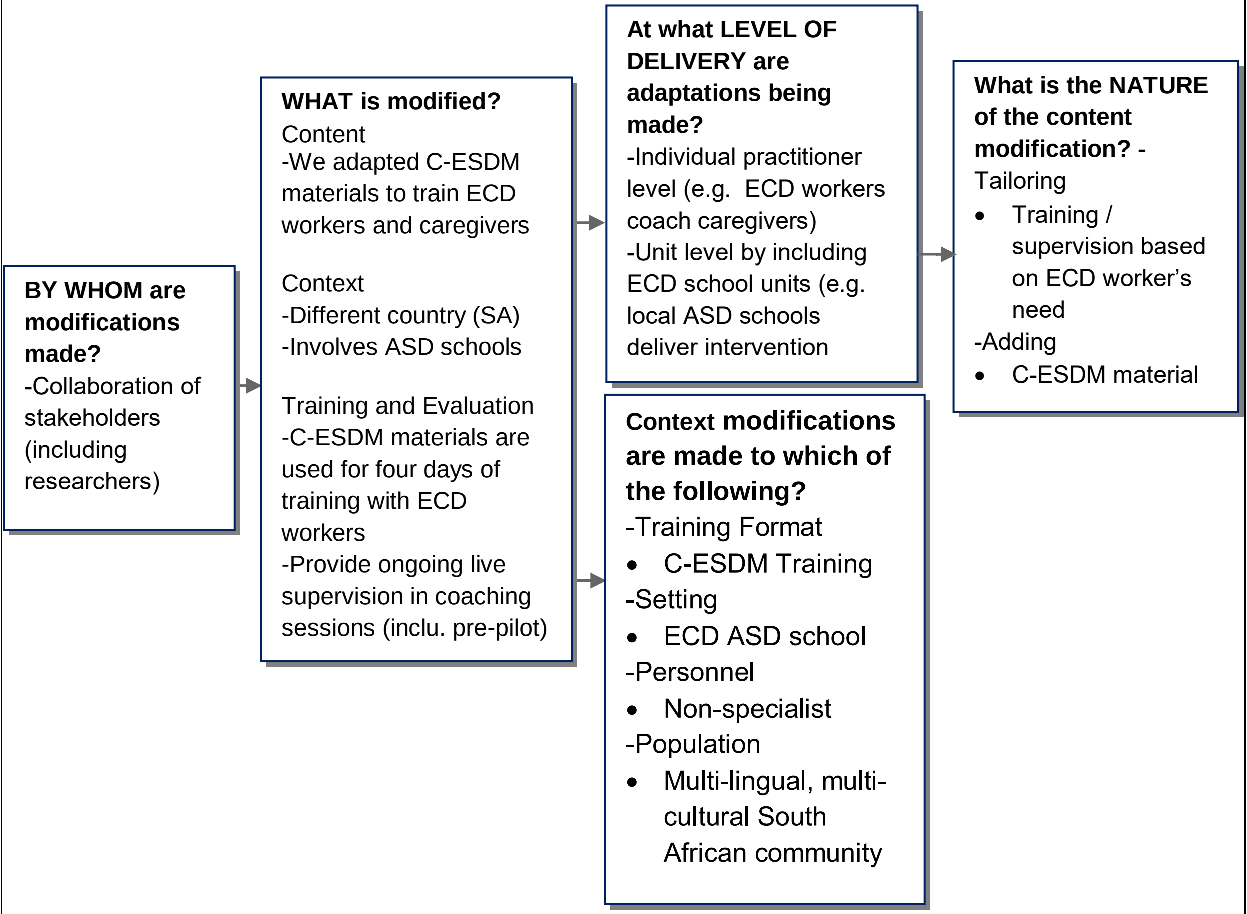
Appendix A

ESDM intervention adaptation for South Africa

Display of caregiver-coaching intervention adaptation process



BY WHOM are modifications made?
-Collaboration of stakeholders (including researchers)

WHAT is modified?
Content
-We adapted C-ESDM materials to train ECD workers and caregivers

Context
-Different country (SA)
-Involves ASD schools

Training and Evaluation
-C-ESDM materials are used for four days of training with ECD workers
-Provide ongoing live supervision in coaching sessions (inclu. pre-pilot)

At what LEVEL OF DELIVERY are adaptations being made?
-Individual practitioner level (e.g. ECD workers coach caregivers)
-Unit level by including ECD school units (e.g. local ASD schools deliver intervention

What is the NATURE of the content modification? -
Tailoring
- Training / supervision based on ECD worker's need

-Adding
- C-ESDM material

Context modifications are made to which of the following?
-Training Format
- C-ESDM Training

-Setting
- ECD ASD school

-Personnel
- Non-specialist

-Population
- Multi-lingual, multi-cultural South African community

Figure 2. This is a published system of classifying modifications to evidence-based interventions cited in (Wiltsey Stirman et al., 2013). It is used here to document a South African adaptation of the Early Start Denver Model (ESDM).
C-ESDM: Caregiver Early Start Denver Model
ECD: Early Childhood Development workers (non-specialist)

Appendix B

Results summary table

Theme	Subtheme
Implementation Facilitators	
1. ECD worker ASD knowledge and experience	Baseline ASD knowledge Skills gained over time from training and coaching
2. Positive coaching experience	In-session caregiver-coaching structure Value of team relationships
3. Clear illustration of intervention concepts from the videos	Illustration of intervention skills
4. Mastery and generalisation of skills	Skills mastery by the ECD workers and ECD supervisors Intervention skill mastery by caregivers
Implementation Barriers	
1. Intervention and coaching concepts	Complexity of concepts Misalignment of ECD worker training with caregiver coaching approach
2. Logistical challenges	Time constraints Access to physical resources: dedicated coaching space,
3. Video Content misaligned with South African context	Mismatch of material with South African context
Facilitators to Sustain the Intervention	
1. Child and caregiver outcomes	Child outcomes Caregiver ‘buy-in’ Caregiver competence
2. Structural factors promoting intervention sustainability	Need for ongoing live supervision Feasibility within the school system
Barriers to Sustaining the Intervention	
1. Structural issues	Poverty, transportation, unemployment

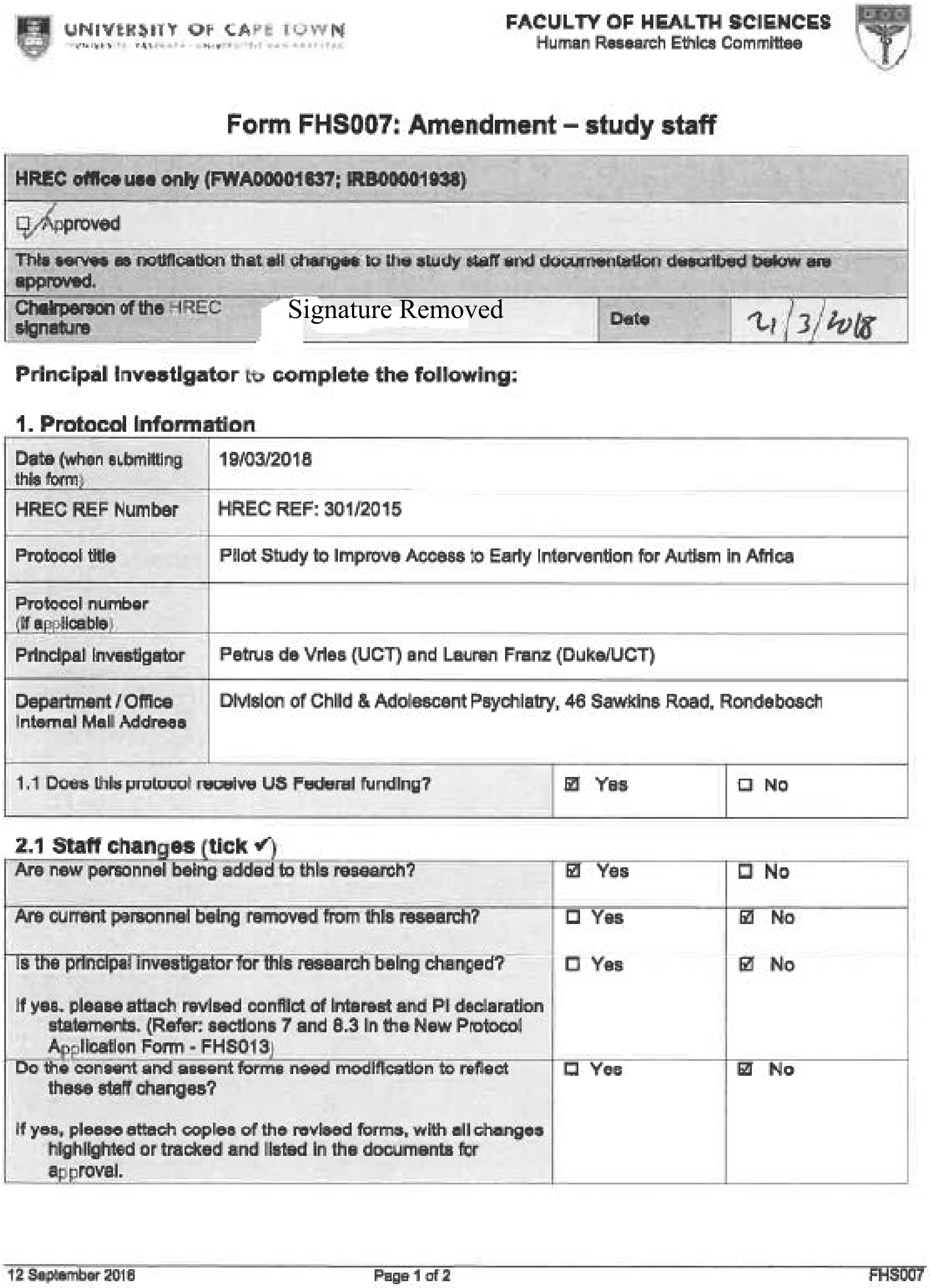
Appendix C

Core interview guides

A - Questions for **caregivers** who receive the intervention i. What was your experience of the therapy? ii. What worked and what didn't work with the therapy? iii. What outcomes did you see or are you seeing in your child? iv. How did the therapy affect your time commitments at home? v. Was it easy or difficult to include therapy in your daily schedule? vi. Can you think of any changes or improvements we can make to the therapy that would make it easier for you to use in your home? vii. Will you be able to continue using the therapy with your child when the project is finished? Why or why not? viii. What was your experience of the videos? ix. What worked and what didn't work with the videos? x. Can you think of any changes or improvements we can make to the videos? xi. Did the fact that these were American families and children in the videos affect how you felt about the videos?	**B** - Question for **early childhood development practitioners** who deliver the intervention i. How did the therapy work in your school? ii. What worked and what didn't work? iii. How did it affect your workload, burden and space? iv. What do you and others in your school think about the therapy, and how has that changed over time? v. What outcomes did you see in the children you are working with? vi. What changes should we make to the therapy or the training? vii. Do you think you will continue using the therapy when the study is over? Why or why not? viii. What was your experience of the videos? ix. What worked and what didn't work with the videos? x. Can you think of any changes or improvements we can make to the videos? xi. Did the fact that these were American families and children in the videos affect how you felt about the videos?
C - Questions for **school supervisors of early childhood development practitioners** i. How did the therapy work in your school? ii. What worked and what didn't work? iii. How did the therapy affect workload, burden, and space? iv. What do you and others in your school think about the therapy, and how has that changed over time? v. What outcomes did you see in the children the ECD practitioners are working with? vi. What changes should be made to the therapy or training? vii. Do you think your school will continue using the therapy when the study is over? Why or why not? viii. What was your experience of the videos? ix. What worked and what didn't work with the videos? x. Can you think of any changes or improvements we can make to the videos? xi. Did the fact that these were American families and children in the videos affect how you felt about the videos?	**D** - Questions for **certified Early Start Denver Model therapists** who provide the training and supervision i. How did ESDM operate in the schools? ii. What worked and what didn't work? iii. How did ESDM affect workload, burden and space in the schools? iv. How was ESDM received by those who worked with it in the schools, and how did that change over time? v. What outcomes did you see or are you seeing in the children? vi. Was there feedback and what was it? / What feedback did you obtain? vii. What changes should be made to the ESDM training you led, the supervision you are providing, or the session structure? viii. Do you see think ESDM would be sustainable in the school setting? ix. What was your experience of the videos? x. What worked and what didn't work with the videos? xi. Can you think of any changes or improvements we can make to the videos? xii. Did the fact that these were American families and children in the videos affect how you felt about the videos?

Appendix D

University of Cape Town Human Research Ethics Council (HREC) protocol p.1 of 2



UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

Form FHS007: Amendment – study staff

HREC office use only (FWA00001637; IRB00001938)			
☑ Approved			
This serves as notification that all changes to the study staff and documentation described below are approved.			
Chairperson of the HREC signature	Signature Removed	**Date**	21/3/2018

Principal Investigator to complete the following:

1. Protocol Information

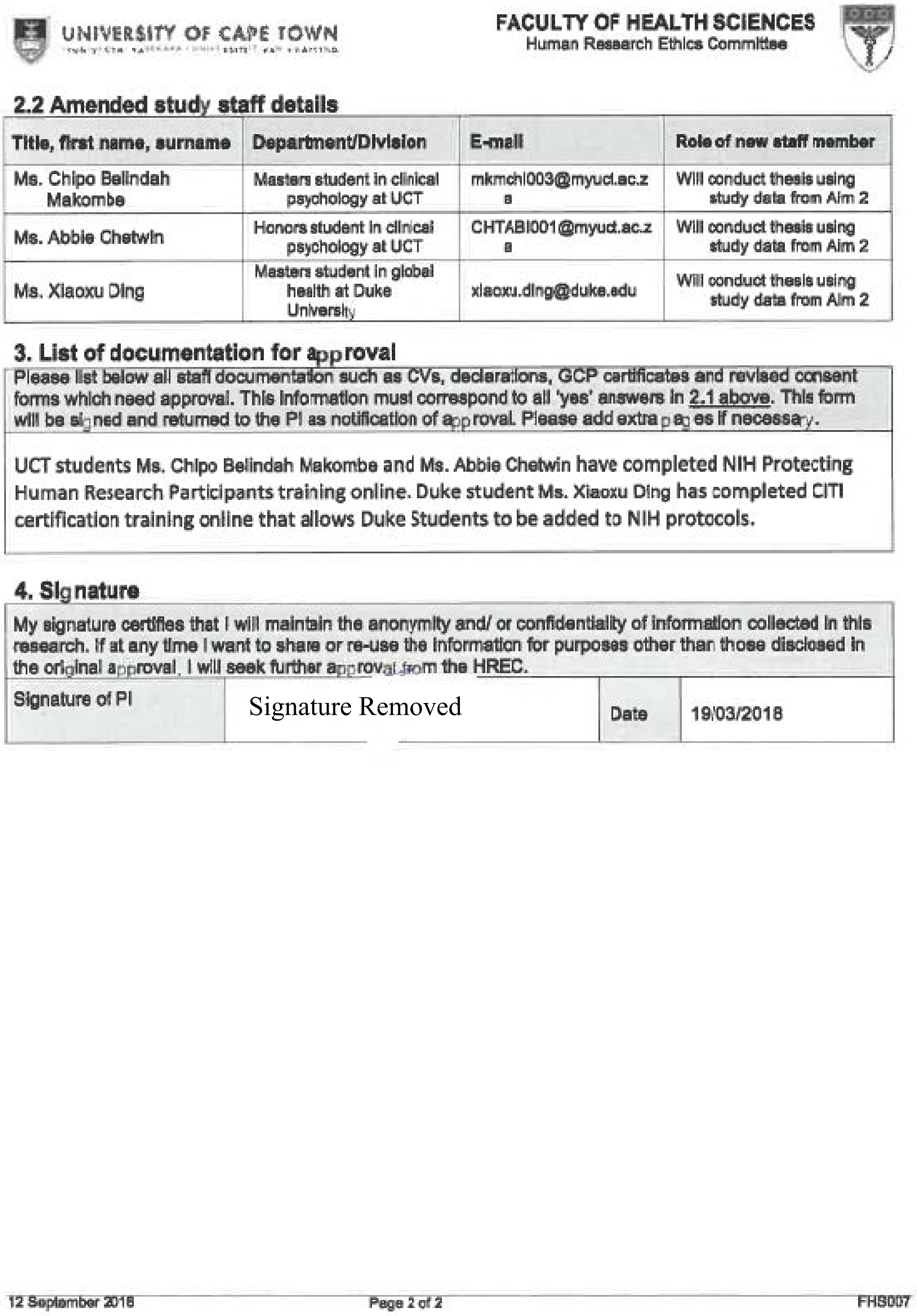
Date (when submitting this form)	19/03/2018	
HREC REF Number	HREC REF: 301/2015	
Protocol title	Pilot Study to Improve Access to Early Intervention for Autism in Africa	
Protocol number (if applicable)		
Principal Investigator	Petrus de Vries (UCT) and Lauren Franz (Duke/UCT)	
Department / Office Internal Mail Address	Division of Child & Adolescent Psychiatry, 46 Sawkins Road, Rondebosch	
1.1 Does this protocol receive US Federal funding?	☑ Yes	☐ No

2.1 Staff changes (tick ✓)

Are new personnel being added to this research?	☑ Yes	☐ No
Are current personnel being removed from this research?	☐ Yes	☑ No
Is the principal investigator for this research being changed? If yes, please attach revised conflict of interest and PI declaration statements. (Refer: sections 7 and 8.3 in the New Protocol Application Form - FHS013)	☐ Yes	☑ No
Do the consent and assent forms need modification to reflect these staff changes? If yes, please attach copies of the revised forms, with all changes highlighted or tracked and listed in the documents for approval.	☐ Yes	☑ No

12 September 2016 Page 1 of 2 FHS007

University of Cape Town Human Research Ethics Council (HREC) protocol p.2 of 2



UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

2.2 Amended study staff details

Title, first name, surname	Department/Division	E-mail	Role of new staff member
Ms. Chipo Belindah Makombe	Masters student in clinical psychology at UCT	mkmchi003@myuct.ac.za	Will conduct thesis using study data from Aim 2
Ms. Abbie Chetwin	Honors student in clinical psychology at UCT	CHTABI001@myuct.ac.za	Will conduct thesis using study data from Aim 2
Ms. Xiaoxu Ding	Masters student in global health at Duke University	xiaoxu.ding@duke.edu	Will conduct thesis using study data from Aim 2

3. List of documentation for approval

Please list below all staff documentation such as CVs, declarations, GCP certificates and revised consent forms which need approval. This information must correspond to all 'yes' answers in 2.1 above. This form will be signed and returned to the PI as notification of approval. Please add extra pages if necessary.

UCT students Ms. Chipo Belindah Makombe and Ms. Abbie Chetwin have completed NIH Protecting Human Research Participants training online. Duke student Ms. Xiaoxu Ding has completed CITI certification training online that allows Duke Students to be added to NIH protocols.

4. Signature

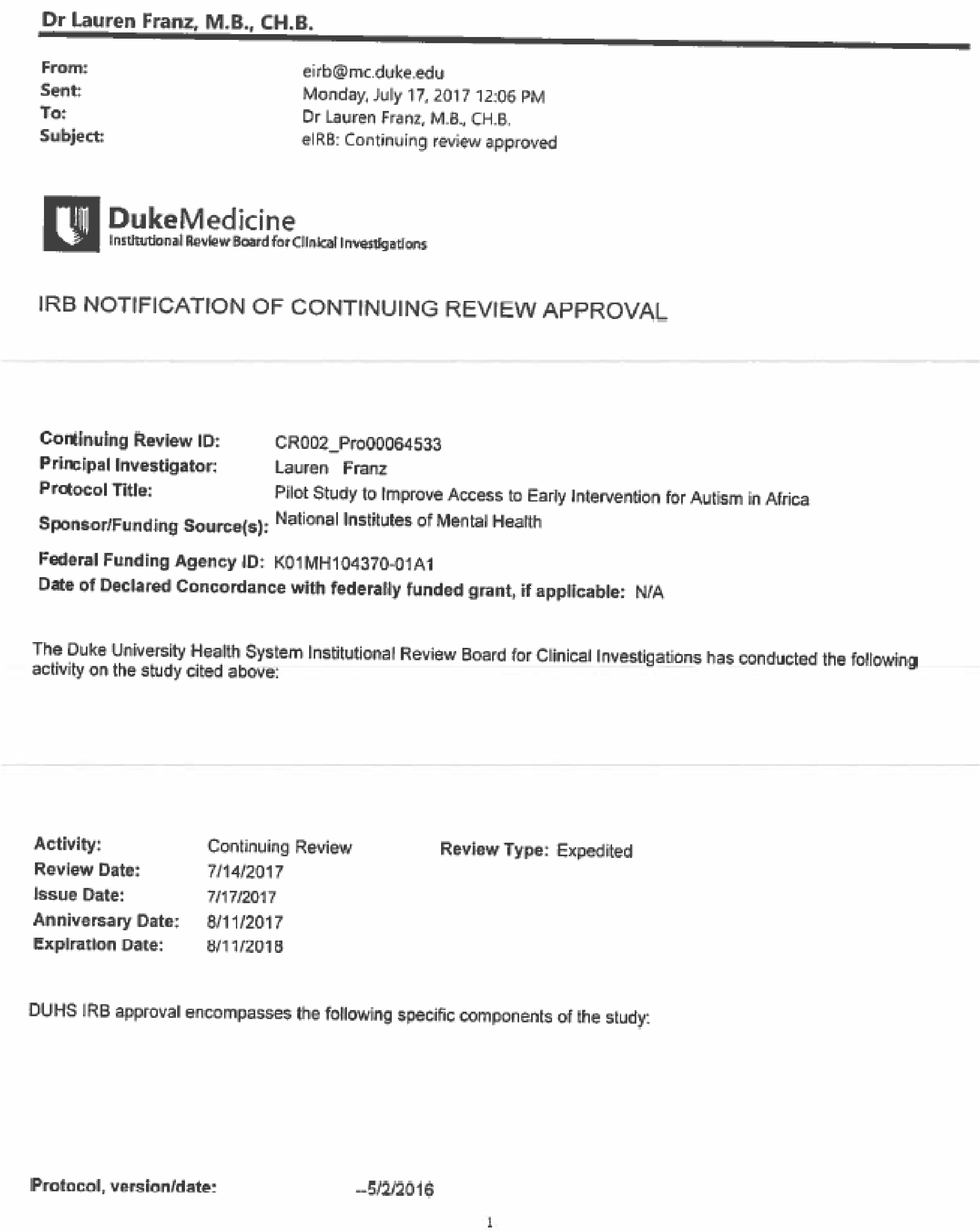
My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.

Signature of PI	Signature Removed	Date	19/03/2018

12 September 2016 Page 2 of 2 FHS007

Appendix E

Duke University Institutional Review Board (IRB) protocol p.1 of 2



Dr Lauren Franz, M.B., CH.B.

From: eirb@mc.duke.edu
Sent: Monday, July 17, 2017 12:06 PM
To: Dr Lauren Franz, M.B., CH.B.
Subject: eIRB: Continuing review approved

DukeMedicine
Institutional Review Board for Clinical Investigations

IRB NOTIFICATION OF CONTINUING REVIEW APPROVAL

Continuing Review ID: CR002_Pro00064533
Principal Investigator: Lauren Franz
Protocol Title: Pilot Study to Improve Access to Early Intervention for Autism in Africa
Sponsor/Funding Source(s): National Institutes of Mental Health

Federal Funding Agency ID: K01MH104370-01A1
Date of Declared Concordance with federally funded grant, if applicable: N/A

The Duke University Health System Institutional Review Board for Clinical Investigations has conducted the following activity on the study cited above:

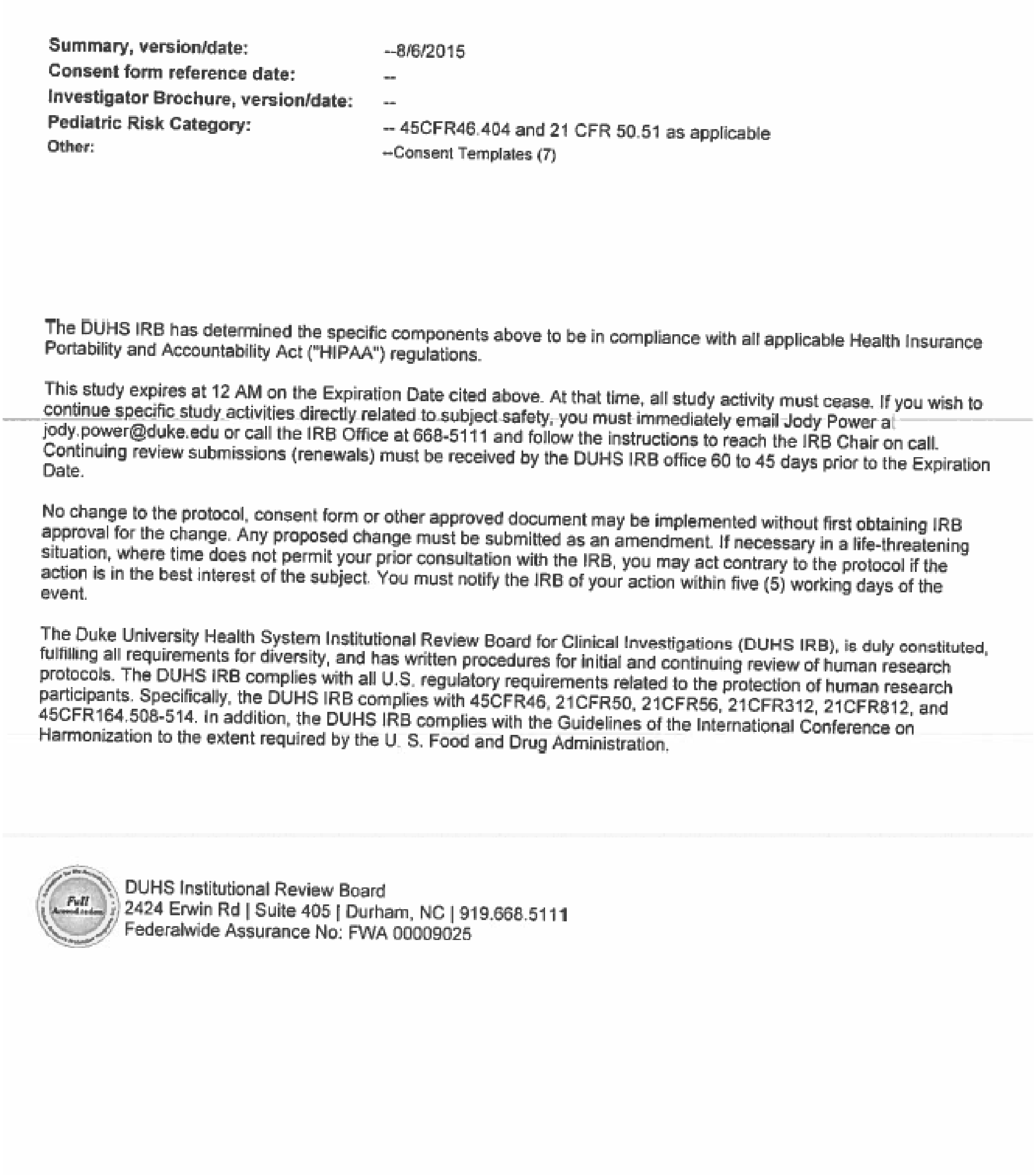
Activity: Continuing Review **Review Type:** Expedited
Review Date: 7/14/2017
Issue Date: 7/17/2017
Anniversary Date: 8/11/2017
Expiration Date: 8/11/2018

DUHS IRB approval encompasses the following specific components of the study:

Protocol, version/date: --5/2/2016

1

Duke University Institutional Review Board (IRB) protocol p.2 of 2



Summary, version/date:	--8/6/2015
Consent form reference date:	--
Investigator Brochure, version/date:	--
Pediatric Risk Category:	-- 45CFR46.404 and 21 CFR 50.51 as applicable
Other:	--Consent Templates (7)

The DUHS IRB has determined the specific components above to be in compliance with all applicable Health Insurance Portability and Accountability Act ("HIPAA") regulations.

This study expires at 12 AM on the Expiration Date cited above. At that time, all study activity must cease. If you wish to continue specific study activities directly related to subject safety, you must immediately email Jody Power at jody.power@duke.edu or call the IRB Office at 668-5111 and follow the instructions to reach the IRB Chair on call. Continuing review submissions (renewals) must be received by the DUHS IRB office 60 to 45 days prior to the Expiration Date.

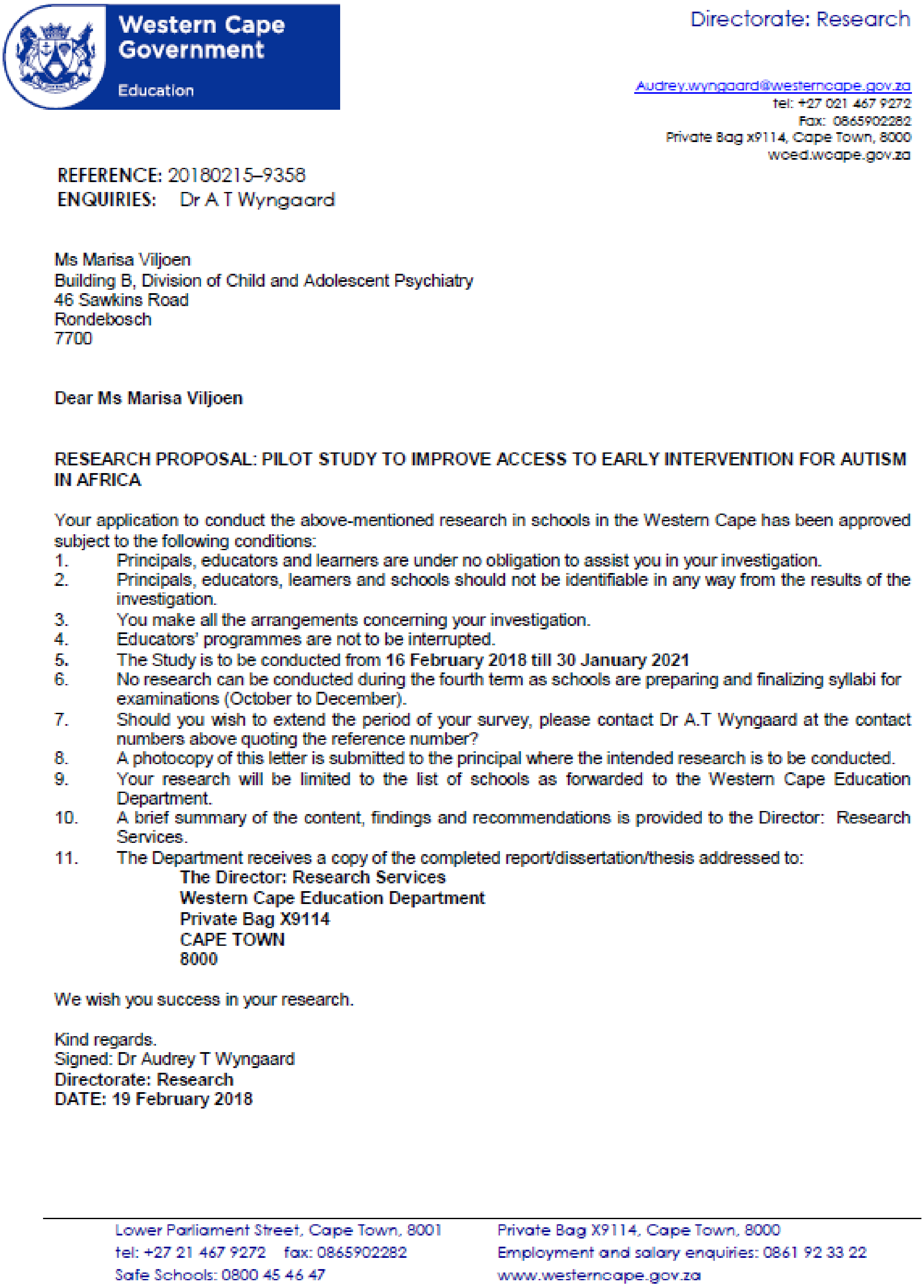
No change to the protocol, consent form or other approved document may be implemented without first obtaining IRB approval for the change. Any proposed change must be submitted as an amendment. If necessary in a life-threatening situation, where time does not permit your prior consultation with the IRB, you may act contrary to the protocol if the action is in the best interest of the subject. You must notify the IRB of your action within five (5) working days of the event.

The Duke University Health System Institutional Review Board for Clinical Investigations (DUHS IRB), is duly constituted, fulfilling all requirements for diversity, and has written procedures for initial and continuing review of human research protocols. The DUHS IRB complies with all U.S. regulatory requirements related to the protection of human research participants. Specifically, the DUHS IRB complies with 45CFR46, 21CFR50, 21CFR56, 21CFR312, 21CFR812, and 45CFR164.508-514. In addition, the DUHS IRB complies with the Guidelines of the International Conference on Harmonization to the extent required by the U. S. Food and Drug Administration.

DUHS Institutional Review Board
2424 Erwin Rd | Suite 405 | Durham, NC | 919.668.5111
Federalwide Assurance No: FWA 00009025

Appendix F

Western Cape Department of Education approval



Western Cape Government
Education

Directorate: Research

Audrey.wyngaard@westerncape.gov.za
tel: +27 021 467 9272
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

REFERENCE: 20180215–9358
ENQUIRIES: Dr A T Wyngaard

Ms Marisa Viljoen
Building B, Division of Child and Adolescent Psychiatry
46 Sawkins Road
Rondebosch
7700

Dear Ms Marisa Viljoen

RESEARCH PROPOSAL: PILOT STUDY TO IMPROVE ACCESS TO EARLY INTERVENTION FOR AUTISM IN AFRICA

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **16 February 2018 till 30 January 2021**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000

We wish you success in your research.

Kind regards.
Signed: Dr Audrey T Wyngaard
Directorate: Research
DATE: 19 February 2018

Lower Parliament Street, Cape Town, 8001
tel: +27 21 467 9272 fax: 0865902282
Safe Schools: 0800 45 46 47

Private Bag X9114, Cape Town, 8000
Employment and salary enquiries: 0861 92 33 22
www.westerncape.gov.za

Appendix G

Humanities: Department of Psychology Research Ethics Committee clearance

Faculty of Humanities
Postgraduate Administration
University of Cape Town

Room 110, Beattie Building
Private Bag X3, Rondebosch 7701
Tel: +27 (0) 21 650 2693
E-mail: sylvia.chauke@uct.ac.za
Website:http://www.humanities.uct.ac.za/hum/postgraduate/studies/aboutus/overview

23 April 2018

Miss Chipo Makombe
E-mail: MKMCHI003@MYUCT.AC.ZA
Student no.: MKMCHI003

Dear Miss Makombe

ACCEPTANCE OF MASTERS PROPOSAL BY HUMANITIES FACULTY BOARD

I have pleasure in advising that your research proposal as detailed below has been approved by the department, and the Faculty of Humanities in the Dean's Circular HUM 01/2018.

Kind regards
Sylvia.chauke@uct.ac.za
Miss Sylvia Chauke
Faculty of Humanities: Postgraduate office

cc Supervisor/s: Dr N Shabalala
Co-Supervisor: Dr L Franz

CANDIDATE	STUDENT NO.	DEPT	SUPERVISOR	CO-SUPERVISOR	TITLE
Makombe, CBT	MKMCHI003	PSY	Dr N Shabalala	Dr L Franz	Barriers and facilitators of an early autism intervention implementation: a South African context

"Our Mission is to be an outstanding teaching and research university, educating for life and addressing the challenges facing our society."

Appendix H

National Institute of Health (NIH) web-based training certificate

Certificate of Completion

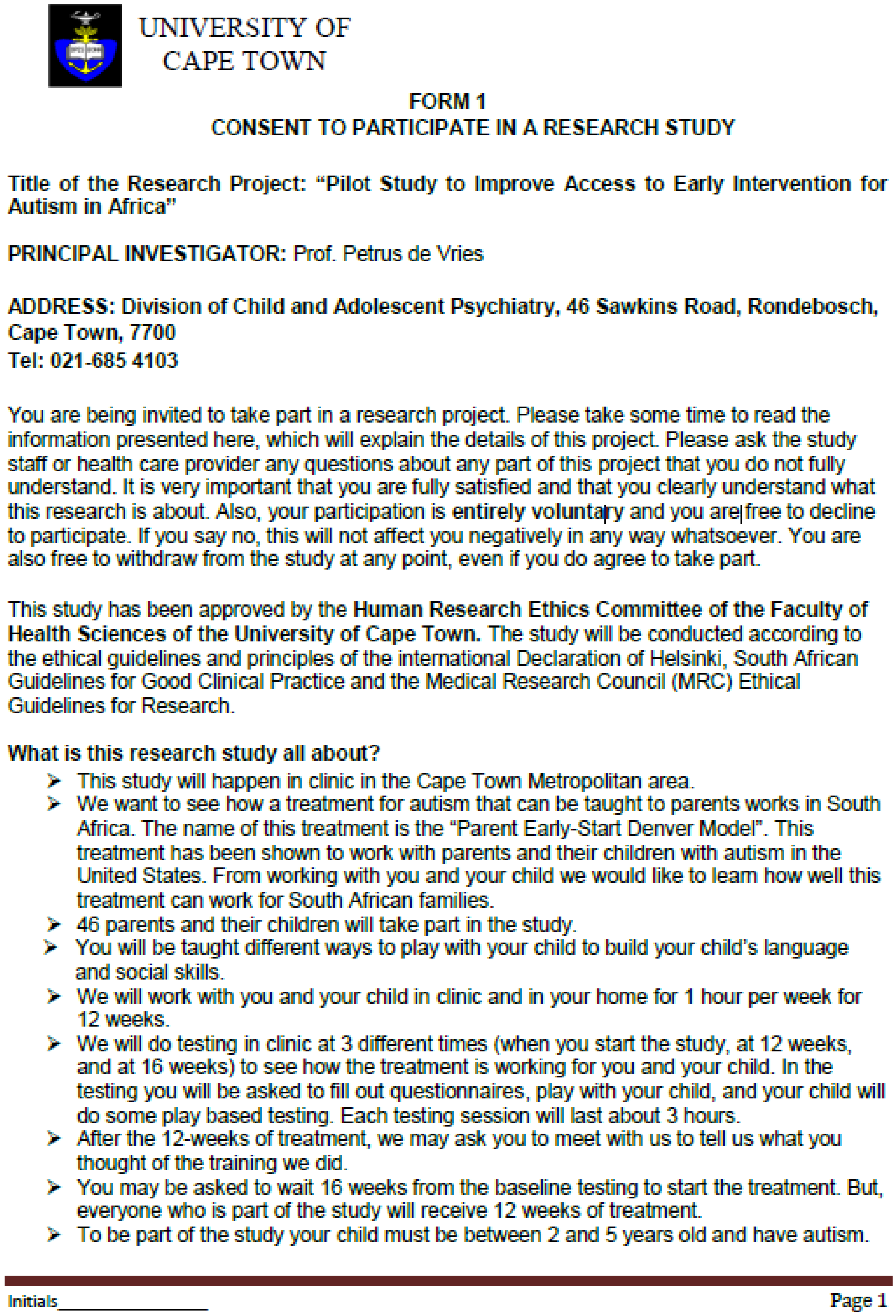
The National Institutes of Health (NIH) Office of Extramural Research certifies that **Chipo Belindah Theodorah Makombe** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 03/11/2018.

Certification Number: 2676534.

Appendix I

Consent to participate in a research study p.1 of 6



UNIVERSITY OF
CAPE TOWN

FORM 1
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of the Research Project: "Pilot Study to Improve Access to Early Intervention for Autism in Africa"

PRINCIPAL INVESTIGATOR: Prof. Petrus de Vries

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

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.

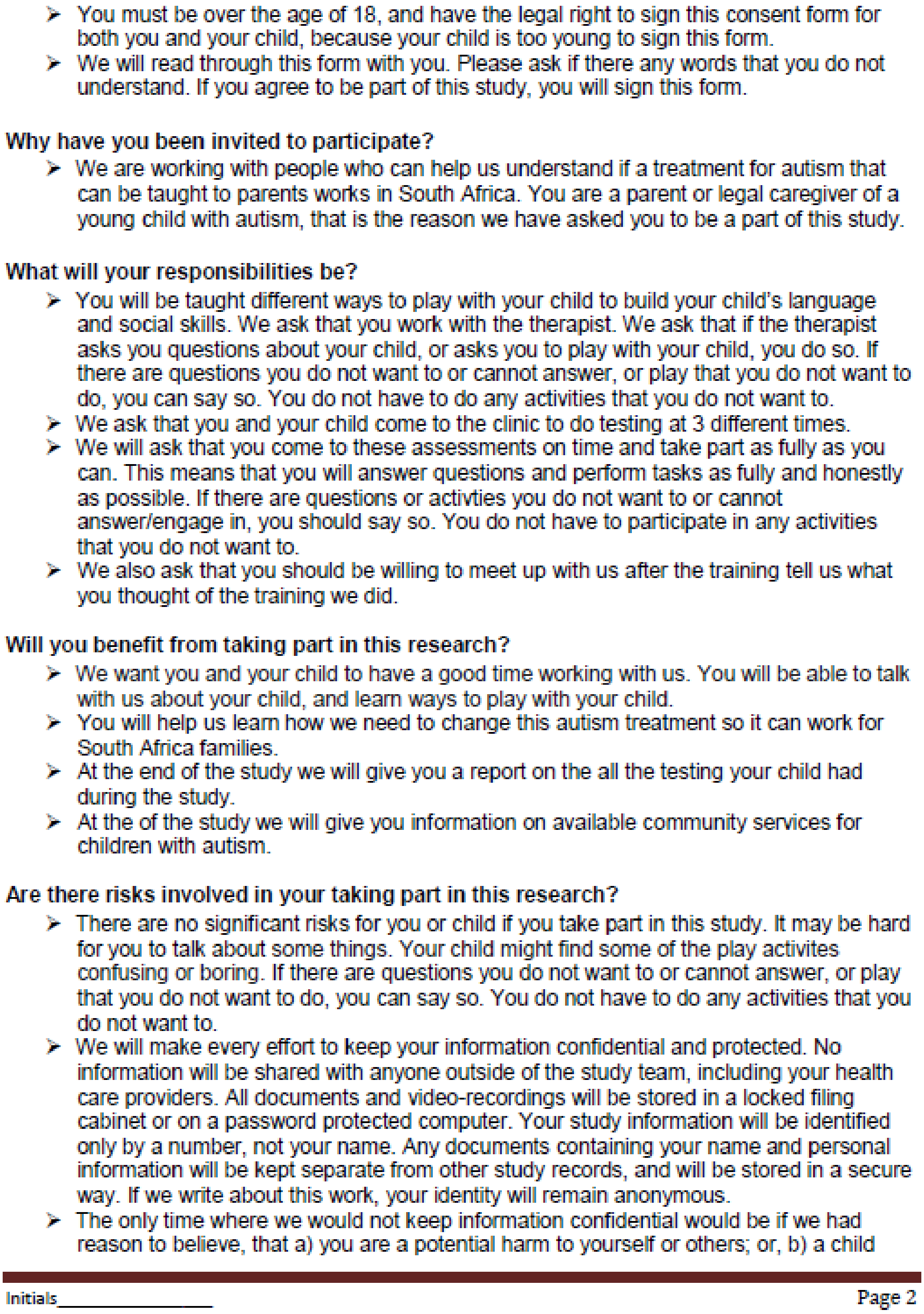
This study has been approved by the **Human Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town.** The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical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

What is this research study all about?

- This study will happen in clinic in the Cape Town Metropolitan area.
- We want to see how a treatment for 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.
- 46 parents and their children will take part in the study.
- 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 in clinic and in your home for 1 hour per week for 12 weeks.
- We will do testing in clinic at 3 different times (when you start the study, at 12 weeks, and at 16 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 may be asked to wait 16 weeks from the baseline testing to start the treatment. But, everyone who is part of the study will receive 12 weeks of treatment.
- To be part of the study your child must be between 2 and 5 years old and have autism.

Initials________________ **Page 1**

Consent to participate in a research study p.2 of 6



- 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 if a treatment for autism that can be taught to parents works in South Africa. You are a parent or legal caregiver of a young child with autism, that is the reason we have asked you to be a part of this study.

What will your responsibilities be?

- You will be taught different ways to play with your child to build your child's language and social skills. We ask that you work with the therapist. We ask that if the therapist asks you questions about your child, or asks you to play with your child, you do so. 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 ask that you and your child come to the clinic to do testing at 3 different times.
- We will ask that you come to these assessments 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.
- We also ask that you should be willing to meet up with us after the training tell us what you thought of the training we did.

Will you benefit from taking part in this research?

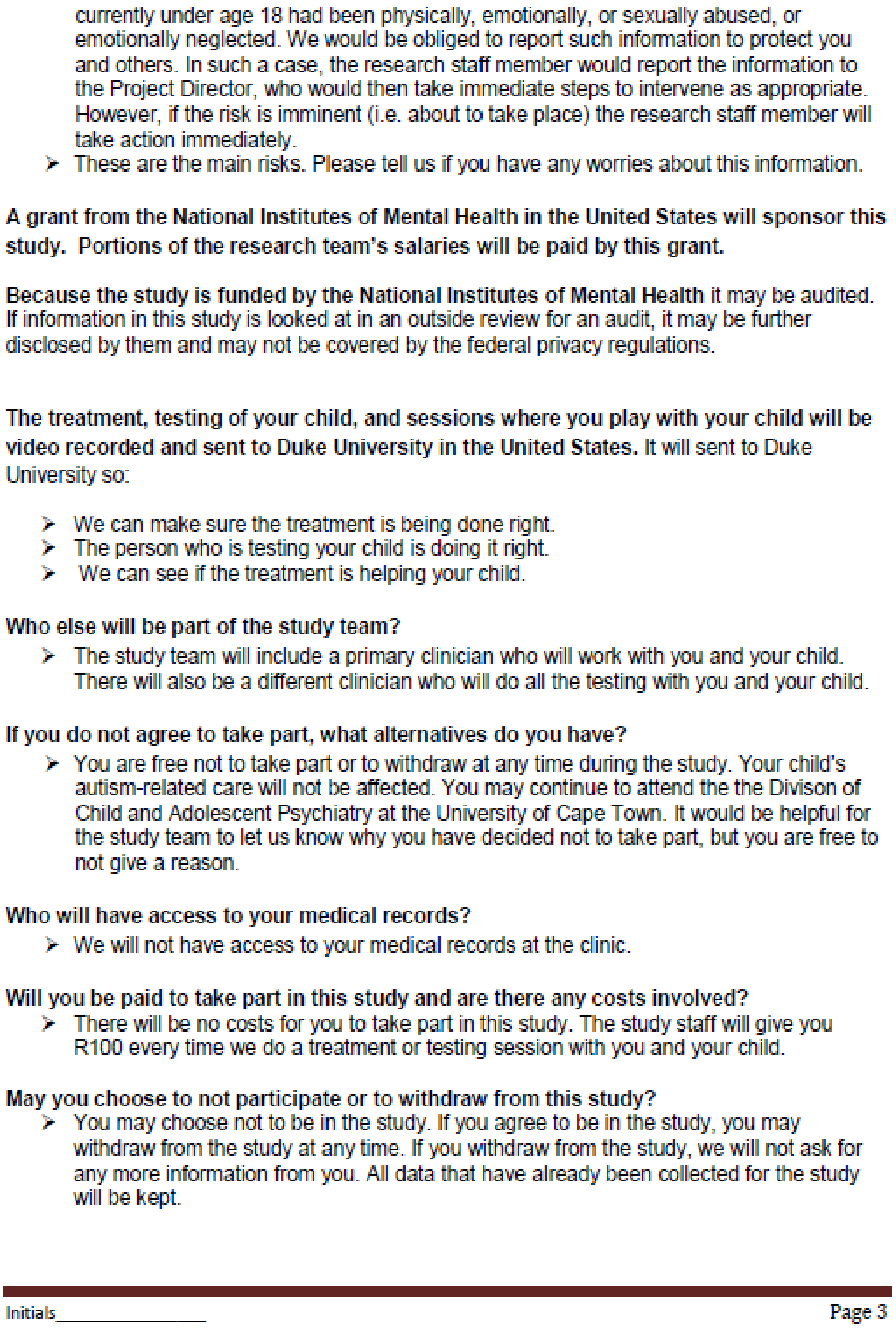
- We want you and your child to have a good time working with us. You will be able to talk with us about your child, and learn ways to play with your child.
- You will help us learn how we need to change this autism treatment so it can work for South Africa families.
- At the end of the study we will give you a report on the all the testing your child had during the study.
- At the of the study we will give you information on available community services for children with autism.

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 video-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

Initials________________ Page 2

Consent to participate in a research study p.3 of 6



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.

The treatment, testing of your child, and sessions where you play with your child will be video recorded and sent to Duke University in the United States. It will sent to Duke University so:

- We can make sure the treatment is being done right.
- The person who is testing your child is doing it right.
- We can see if the treatment is helping your child.

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 autism-related 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?

- We will not have access to your medical records at the clinic.

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

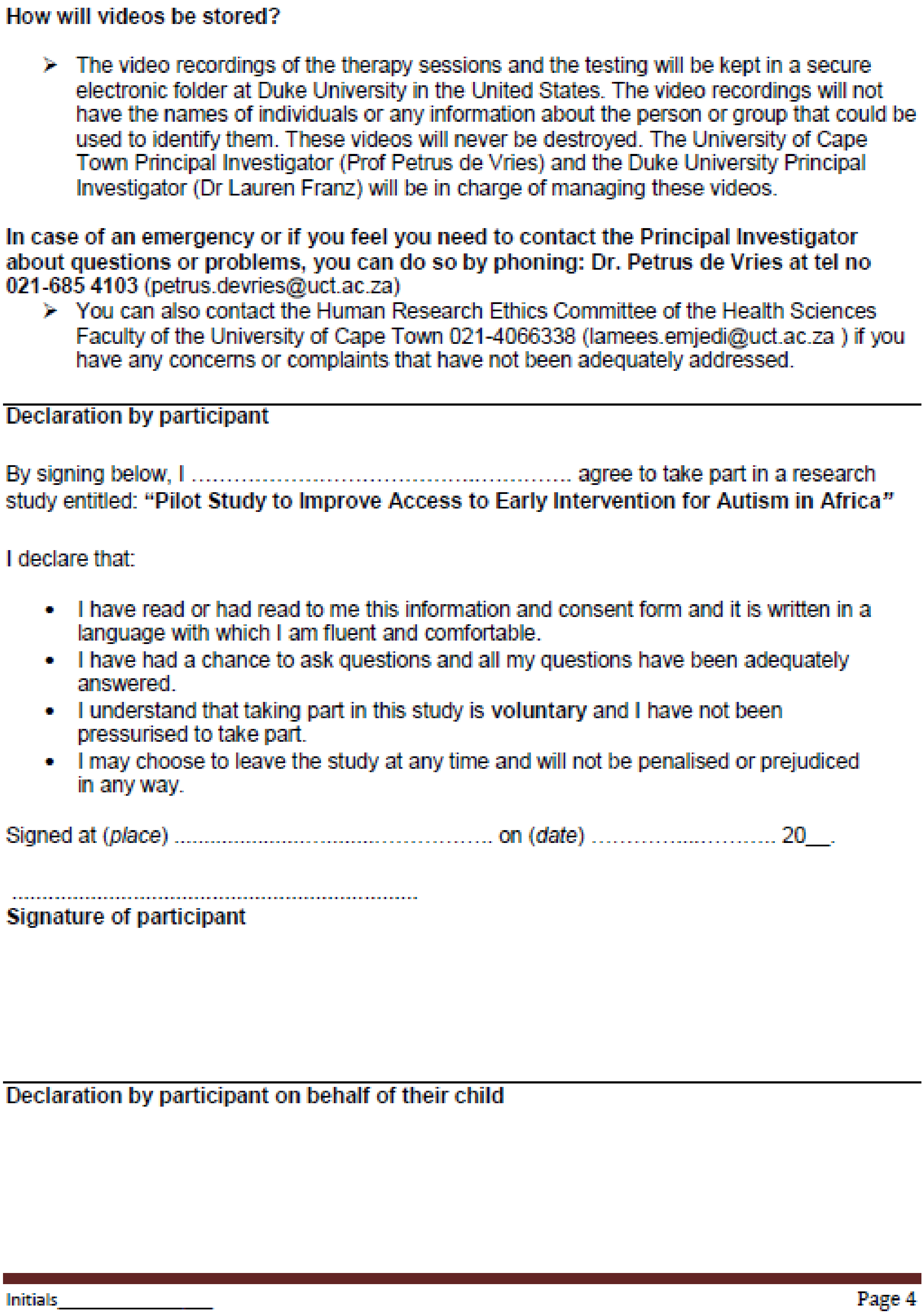
- There will be no costs for you to take part in this study. The study staff will give you R100 every time we do a treatment or testing session with you and your child.

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.

Initials________________

Consent to participate in a research study p.4 of 6



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. Petrus de Vries at tel no 021-685 4103 (petrus.devries@uct.ac.za)

- 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: **"Pilot Study to Improve Access to Early Intervention for Autism 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__.

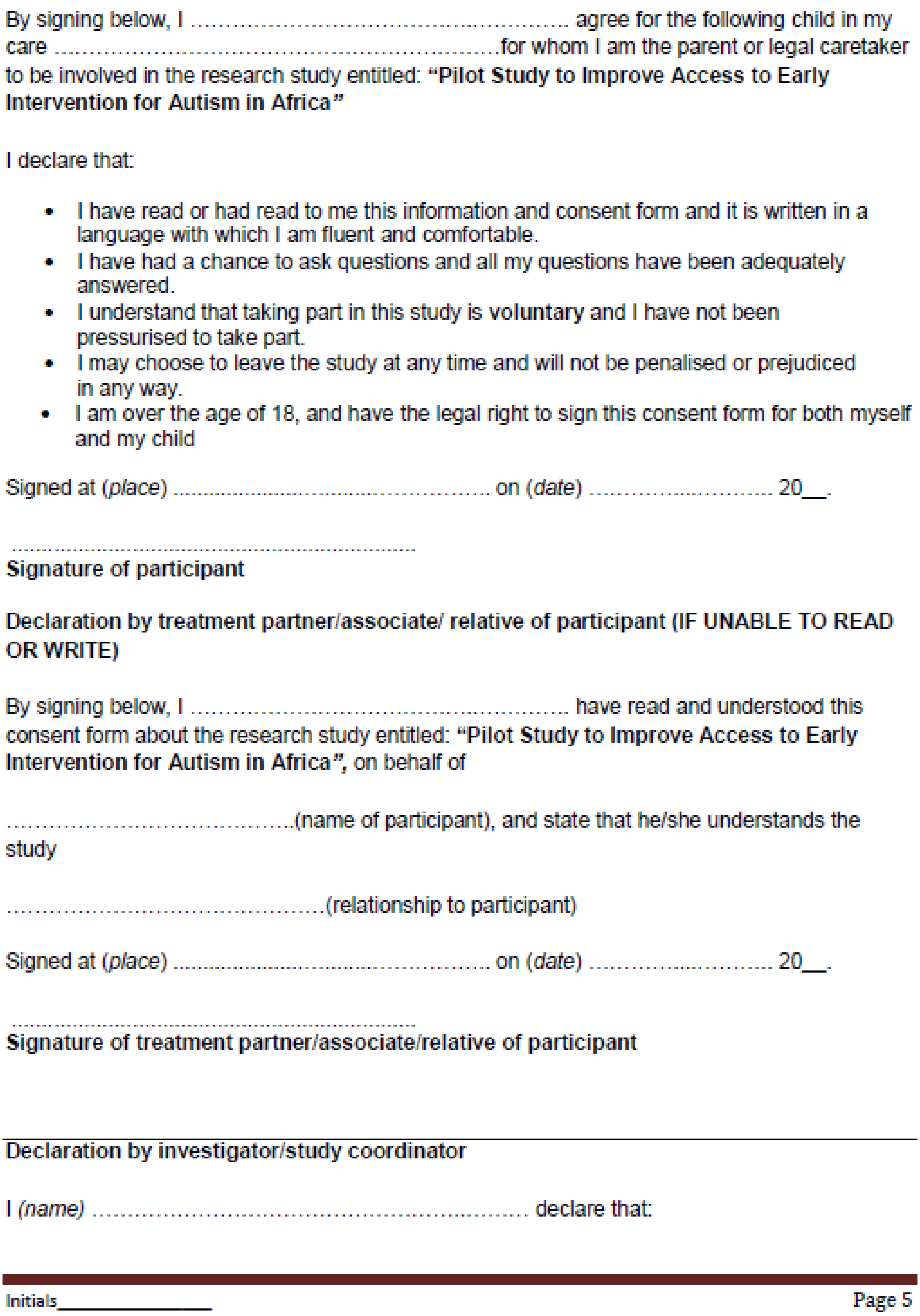
....

Signature of participant

Declaration by participant on behalf of their child

Initials_________________ **Page 4**

Consent to participate in a research study p.5 of 6



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: **"Pilot Study to Improve Access to Early Intervention for Autism 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__.

……………………………………………………………

Signature of participant

Declaration by treatment partner/associate/ relative of participant (IF UNABLE TO READ OR WRITE)

By signing below, I …………………………………………… have read and understood this consent form about the research study entitled: **"Pilot Study to Improve Access to Early Intervention for Autism in Africa",** on behalf of

……………………………………(name of participant), and state that he/she understands the study

…………………………………………(relationship to participant)

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

……………………………………………………………

Signature of treatment partner/associate/relative of participant

---

Declaration by investigator/study coordinator

I *(name)* ……………………………………………………… declare that:

Consent to participate in a research study p.6 of 6

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I will maintain confidentiality at all times.

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

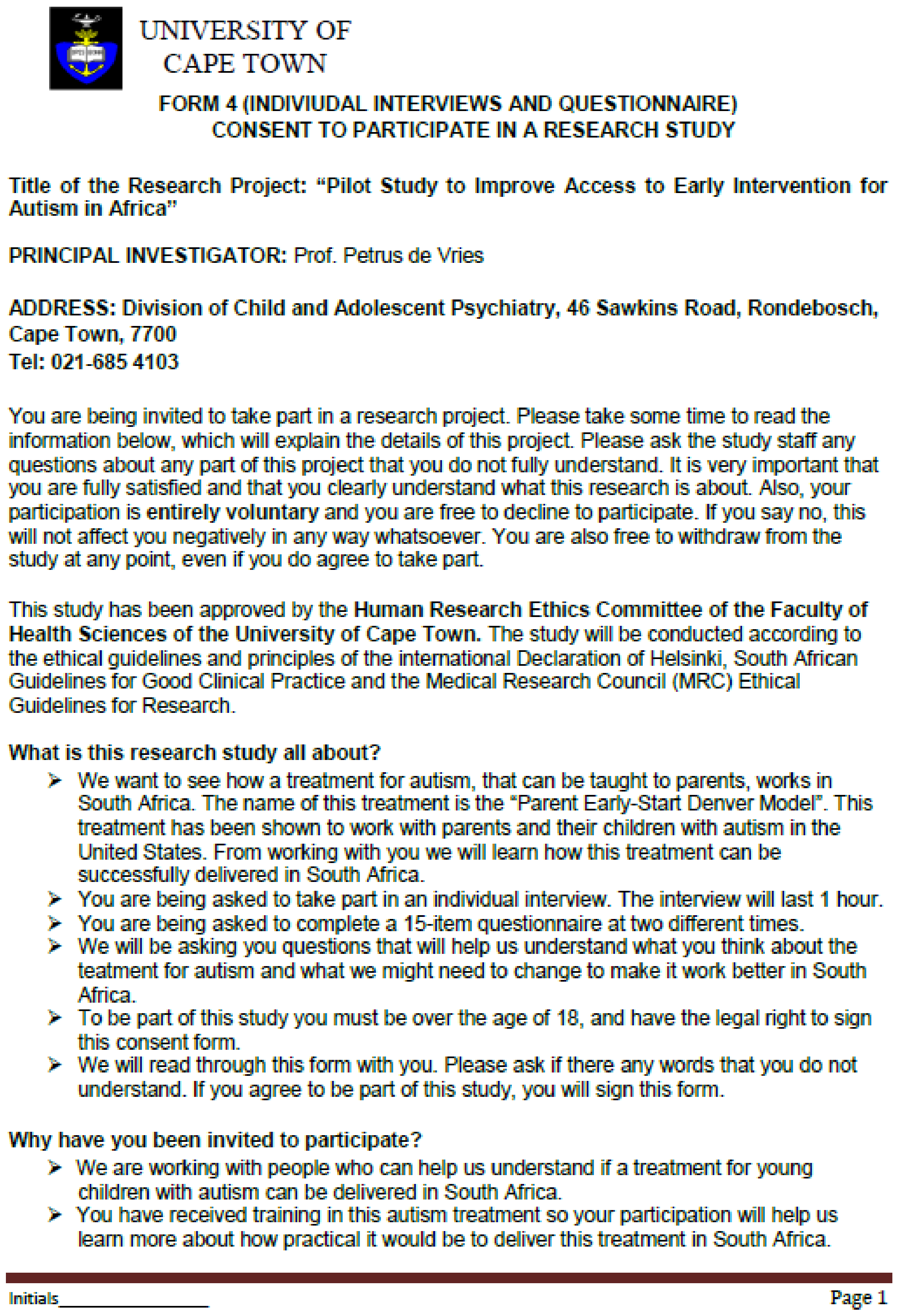
....

Signature of investigator

Initials_______________

Page 6

Consent to individual interviews p.1 of 3



UNIVERSITY OF
CAPE TOWN

FORM 4 (INDIVIUDAL INTERVIEWS AND QUESTIONNAIRE)
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of the Research Project: "Pilot Study to Improve Access to Early Intervention for Autism in Africa"

PRINCIPAL INVESTIGATOR: Prof. Petrus de Vries

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

You are being invited to take part in a research project. Please take some time to read the information below, which will explain the details of this project. Please ask the study staff 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?

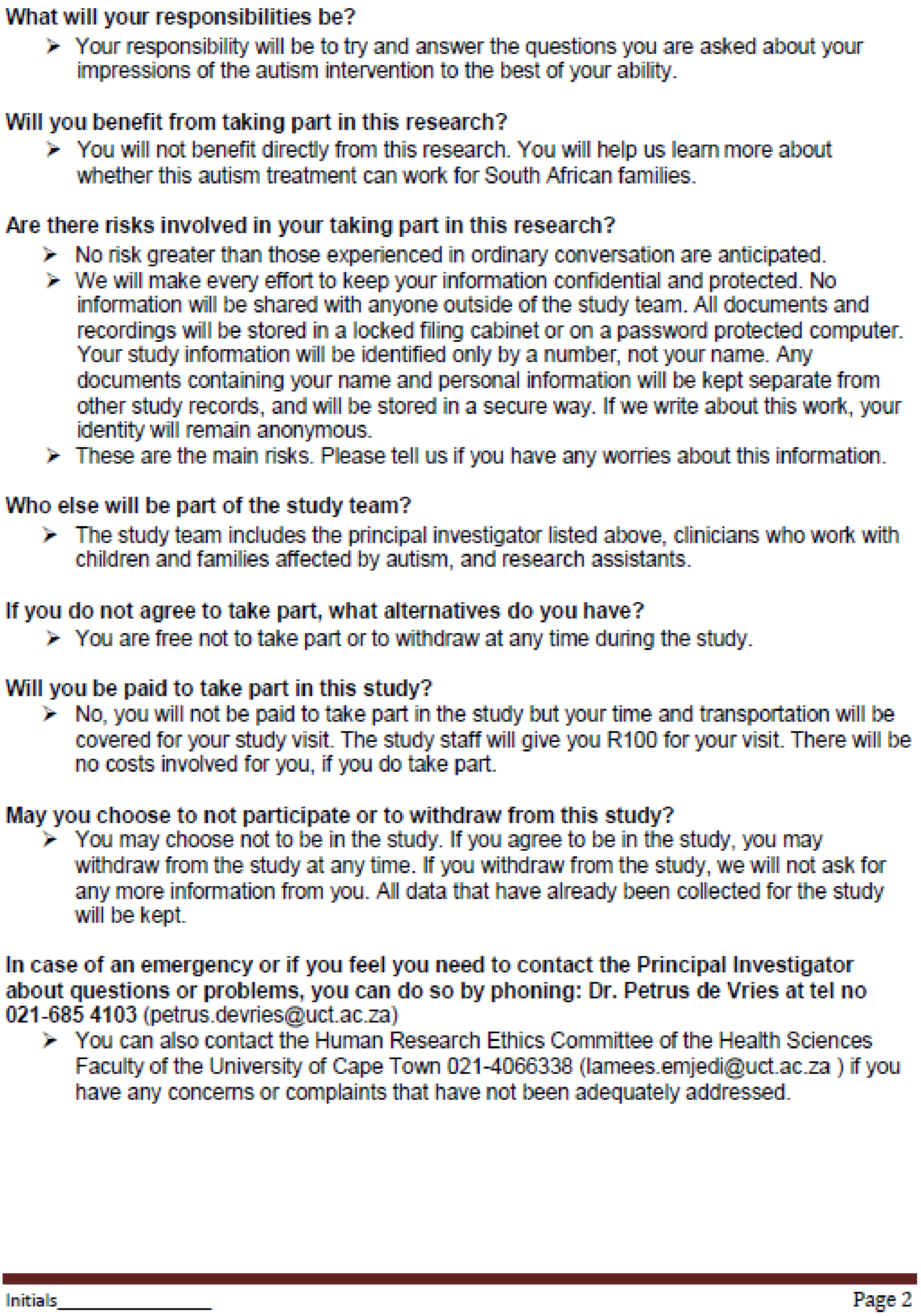
- We want to see how a treatment for autism, that can be taught to parents, works in South Africa. The name of this treatment is the "Parent Early-Start Denver Model". This treatment has been shown to work with parents and their children with autism in the United States. From working with you we will learn how this treatment can be successfully delivered in South Africa.
- You are being asked to take part in an individual interview. The interview will last 1 hour.
- You are being asked to complete a 15-item questionnaire at two different times.
- We will be asking you questions that will help us understand what you think about the teatment for autism and what we might need to change to make it work better in South Africa.
- To be part of this study you must be over the age of 18, and have the legal right to sign this consent 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 if a treatment for young children with autism can be delivered in South Africa.
- You have received training in this autism treatment so your participation will help us learn more about how practical it would be to deliver this treatment in South Africa.

Initials________________ Page 1

Consent to individual interviews p.2 of 3



What will your responsibilities be?

- Your responsibility will be to try and answer the questions you are asked about your impressions of the autism intervention to the best of your ability.

Will you benefit from taking part in this research?

- You will not benefit directly from this research. You will help us learn more about whether this autism treatment can work for South African families.

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

- No risk greater than those experienced in ordinary conversation are anticipated.
- We will make every effort to keep your information confidential and protected. No information will be shared with anyone outside of the study team. 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.
- These are the main risks. Please tell us if you have any worries about this information.

Who else will be part of the study team?

- The study team includes the principal investigator listed above, clinicians who work with children and families affected by autism, and research assistants.

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.

Will you be paid to take part in this study?

- No, you will not be paid to take part in the study but your time and transportation will be covered for your study visit. The study staff will give you R100 for your visit. There will be no costs involved for you, if you do take part.

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.

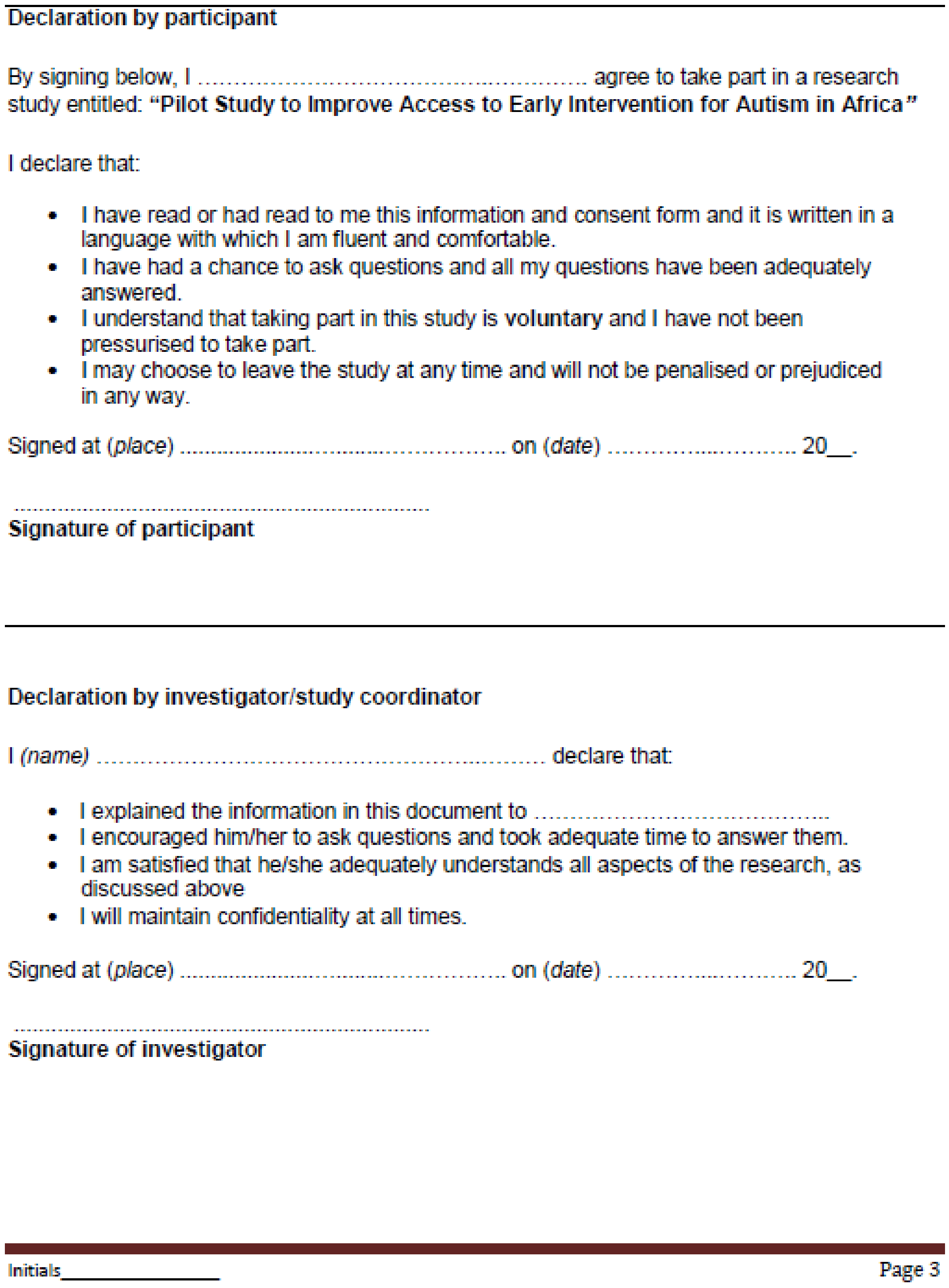
In case of an emergency or if you feel you need to contact the Principal Investigator about questions or problems, you can do so by phoning: Dr. Petrus de Vries at tel no 021-685 4103 (petrus.devries@uct.ac.za)

- 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.

Initials________________

Page 2

Consent to individual interviews p.3 of 3



Declaration by participant

By signing below, I …………………………………………….…………. agree to take part in a research study entitled: **"Pilot Study to Improve Access to Early Intervention for Autism 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 investigator/study coordinator

I *(name)* ……………………………………………………..……… declare that:

- I explained the information in this document to ……………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I will maintain confidentiality at all times.

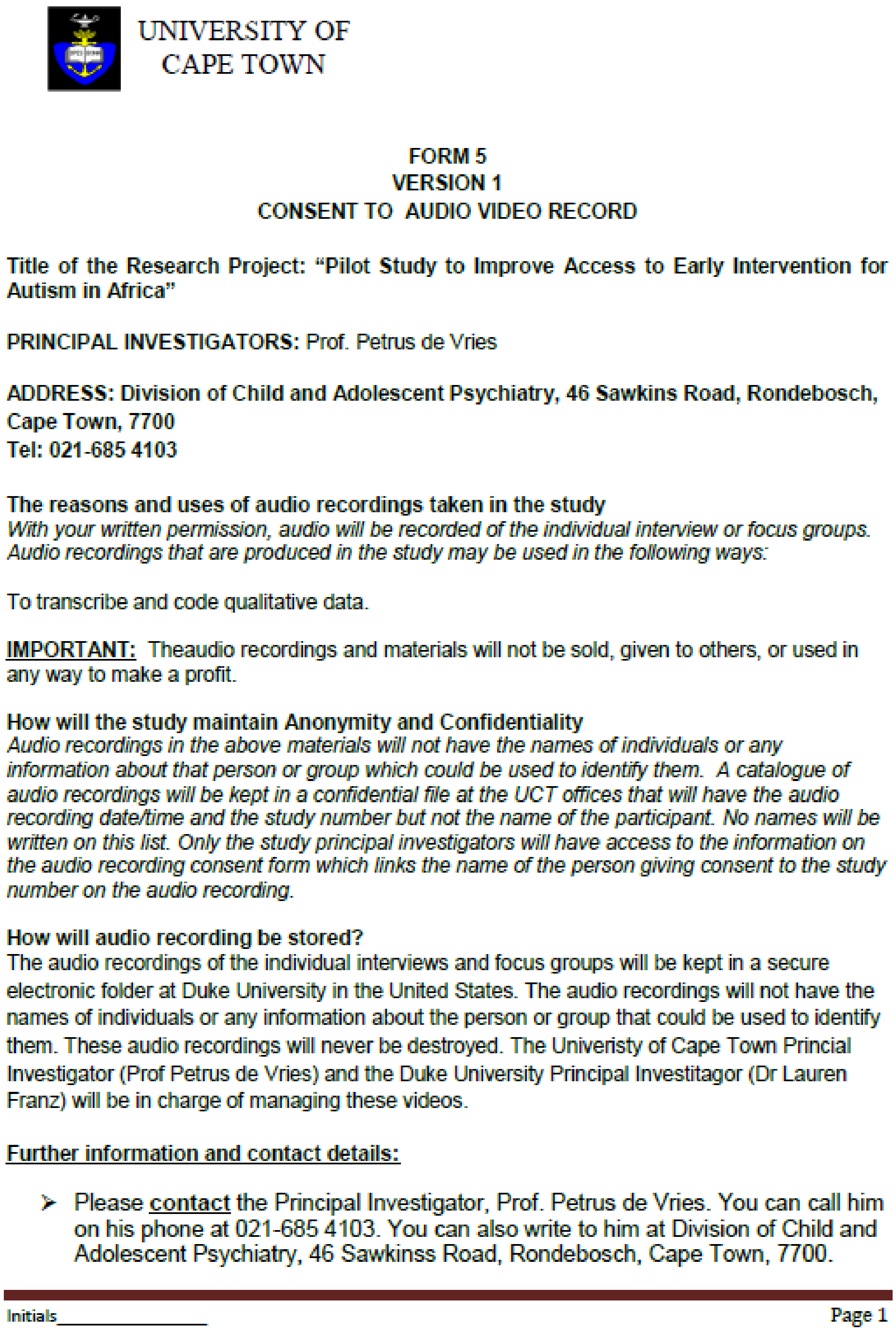
Signed at (*place*) ....…........……………. on (*date*) …………....………. 20__.

....

Signature of investigator

Initials________________ Page 3

Consent to audio record individual interviews p.1 of 2



UNIVERSITY OF
CAPE TOWN

FORM 5
VERSION 1
CONSENT TO AUDIO VIDEO RECORD

Title of the Research Project: "Pilot Study to Improve Access to Early Intervention for Autism in Africa"

PRINCIPAL INVESTIGATORS: Prof. Petrus de Vries

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

The reasons and uses of audio recordings taken in the study
With your written permission, audio will be recorded of the individual interview or focus groups. Audio recordings that are produced in the study may be used in the following ways:

To transcribe and code qualitative data.

IMPORTANT: Theaudio recordings and materials will not be sold, given to others, or used in any way to make a profit.

How will the study maintain Anonymity and Confidentiality
Audio recordings in the above materials will not have the names of individuals or any information about that person or group which could be used to identify them. A catalogue of audio recordings will be kept in a confidential file at the UCT offices that will have the audio recording date/time and the study number but not the name of the participant. No names will be written on this list. Only the study principal investigators will have access to the information on the audio recording consent form which links the name of the person giving consent to the study number on the audio recording.

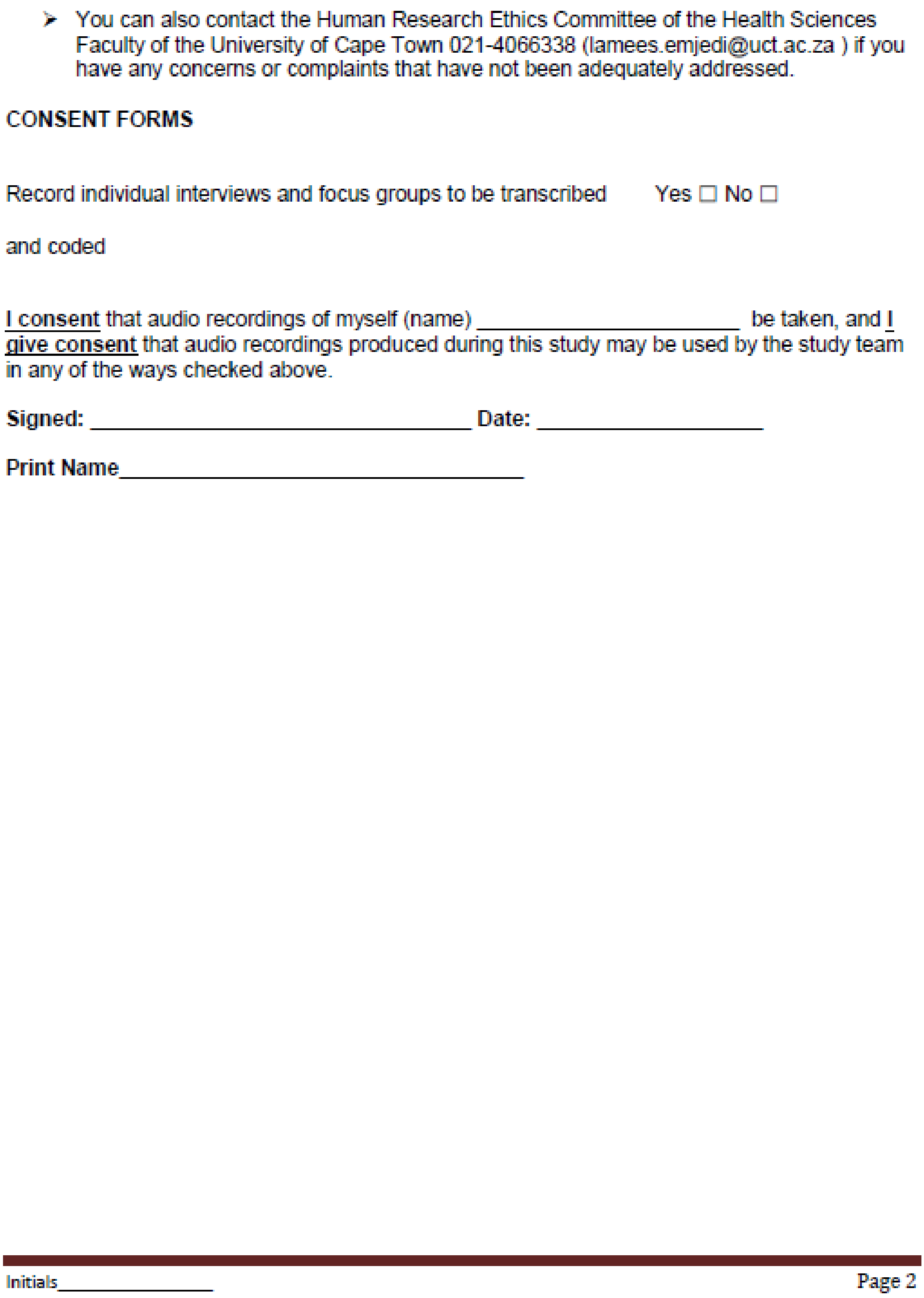
How will audio recording be stored?
The audio recordings of the individual interviews and focus groups will be kept in a secure electronic folder at Duke University in the United States. The audio recordings will not have the names of individuals or any information about the person or group that could be used to identify them. These audio recordings will never be destroyed. The Univeristy of Cape Town Princial Investigator (Prof Petrus de Vries) and the Duke University Principal Investitagor (Dr Lauren Franz) will be in charge of managing these videos.

Further information and contact details:

- Please contact the Principal Investigator, Prof. Petrus de Vries. You can call him on his phone at 021-685 4103. You can also write to him at Division of Child and Adolescent Psychiatry, 46 Sawkinss Road, Rondebosch, Cape Town, 7700.

Initials________________ Page 1

Consent to audio record individual interviews p.2 of 2



- 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.

CONSENT FORMS

Record individual interviews and focus groups to be transcribed Yes ☐ No ☐

and coded

I consent that audio recordings of myself (name) ______________________ be taken, and **I give consent** that audio recordings produced during this study may be used by the study team in any of the ways checked above.

Signed: ________________________________ **Date:** ___________________

Print Name__________________________________

Initials_____________ Page 2

Appendix J

Participant recommended changes to intervention implementation

Barrier to implementation and sustainability category	Recommendation
ECD worker training	• Certified ESDM therapists should commit more time to targeted role play and breakdown of the concepts during the ECD worker training
Logistical challenges	• Parent-coaching to have allocated physical resources (larger venue with a two-way mirror) • Although not explicitly stated, the respondents also seemed to suggest only training ECD workers who are not full-time at a school with other demands • Targeting and training ECD workers with some special needs knowledge and incorporating the ESDM-informed techniques into an already existing school programme with a full-time/dedicated teacher
Videos format and content	• Development of local material that caters to a diverse and multi-lingual population (e.g. Xhosa speaking, local families and children) • Videos developed or used for demonstration must show the differences between children with autism and those without - explain this clearly to the caregivers and ECD trainees • Development of material that also shows a variety of daily tasks and allow the caregiver to practice some of the things s/he does with their child at home using the P-ESDM techniques during the session • Development of a better quality video with bigger font subtitles
Coaching material and building blocks	• The material must include a variety of activities such as gross motor and teaching of safety • Development of material with local persons and with South African languages (Diversity of material)