

Fidelity of Caregiver and Non-specialist Early Autism Intervention Implementation in
South Africa

By:

Xiaoxu Ding

Duke Global Health Institute
Duke University

Date: _____

Approved: _____

Melissa Watt

Joe Egger

Brandon Knettel

Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science in the Duke Global Health Institute
in the Graduate School
of Duke University

2019

ABSTRACT

Fidelity of caregiver and non-specialist early autism intervention implementation in
South Africa

By:

Xiaoxu Ding

Duke Global Health Institute
Duke University

Date: _____
Approved: _____

Melissa Watt

Joe Egger

Brandon Knettel

An abstract of a thesis submitted in partial
fulfillment of the requirements for the degree
of Master of Science in the Duke Global Health Institute
in the Graduate School of
Duke University

2019

Copyright by
Xiaoxu Ding
2019

Abstract

Background: Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder recognized by the World Health Organization as a growing global public health concern. Early interventions such as the Early Start Denver Model (ESDM) can improve intellectual ability, adaptive behaviors and decrease symptom severity in ASD children. In low-resource settings such as South Africa, the lack of autism specialists necessitates early intervention models that can be delivered in-home by caregivers. However, important questions remain as to whether caregivers, coached by non-specialists, can deliver early autism interventions effectively.

Study Aims: The long-term goal of the main ESDM study in South Africa is to advance understanding of the efficacy of caregiver-delivered early autism interventions, coached by non-specialists, in lower-resourced settings. This pre-pilot study aims to: 1) Document adaptations made to a caregiver coaching approach, informed by ESDM principles and delivered by non-specialist providers in South Africa; 2) Examine non-specialist coaching fidelity; and 3) Examine the fidelity of caregiver implementation of ESDM across 12 weeks of intervention sessions.

Methods: Modifications were made to the original ESDM program to improve intervention fit to local settings before the study happened; these adaptations were documented using the Wiltsey-Stirman framework. Two local Early Childhood Development (ECD) workers (non-specialists) and two caregiver-child dyads were recruited to participate in the study in Cape Town, South Africa. There were twelve one-hour sessions of ECD workers coaching caregivers to deliver the intervention with their

children across twelve weeks. Each session was video recorded and then coded following the Caregiver Fidelity Scale and the Coaching Fidelity Scale. In this study, an 80% cutoff line was used to define acceptable fidelity for individual items overall mean scores on the caregiver and coaching fidelity scales.

Results: Both caregivers and ECD Workers met some challenges in certain rating items during intervention sessions. Caregiver 1 met the fidelity threshold for the overall scale in one out of twelve intervention sessions, and caregiver 2 met the threshold in five out of twelve intervention sessions. There was no visible change in the trend of caregiver and coach performances across 12 weeks. ECD Worker 1 met the fidelity threshold for the overall scale in six out of twelve intervention sessions and ECD worker 2 met the threshold in eleven out of twelve sessions.

Conclusion: Using non-specialists to coach caregivers on ASD treatment shows promise as an approach help to reduce the resource gap by providing accessible and affordable early ASD intervention in lower-resource settings. However, additional culturally-sensitive adaptations are needed to make the treatment reach its full potential in a multi-cultural community like South Africa. Given the challenges we observed with intervention fidelity in this setting, training and supervision must continue to be tailored with the intervention to ensure that high quality services are delivered sustainably. If successful, the intervention model has the potential to be scaled up in community settings globally in order to address the needs of young children and families impacted by ASD.

Dedication

To my grandparents, my mom and my favorite actor who supported me through difficult times.

Contents

Abstract.....	iv
List of Figures	ix
List of Tables	ix
Acknowledgements	xi
1. Introduction.....	1
1.1 Autism Spectrum Disorder	1
1.2 Early Intervention for ASD	1
1.3 Naturalistic Developmental Behavioral Interventions and the Early Start Denver Model	3
1.4 Caregiver Delivered Early ASD Intervention.....	4
1.5 Non-specialist providers as caregiver coaches.....	6
1.6 South African early ASD intervention landscape.....	8
1.7 Adaptation and Fidelity	9
1.8 Study Aims	12
2. Methods	14
Overview	14
2.1 Setting.....	15
2.2 Participants.....	15
2.3 Study Design.....	16
2.3.1 Procedures and Data Collection.....	18
2.4 Adaptation.....	21

2.5 Fidelity assessment tools	22
2.5.1 Coaching Fidelity Rating System	22
2.5.2 Caregiver Fidelity Rating System	24
2.6 Data Analysis	26
3. Results.....	27
3.1 Participant Demographics.....	27
3.2 Adaptation of P-ESDM	29
3.3 Fidelity	32
3.3.1 Caregiver Fidelity Scale Scores.....	33
3.3.2 Coaching Fidelity Scale Scores	37
4. Discussion	42
4.1 Future Implications	46
4.2 Limitations.....	47
5. Conclusion.....	50
6. Appendix.....	51
Coaching Fidelity Scale.....	51
Caregiver Fidelity Scale	53
7. References.....	57

List of Figures

Figure 2.3. 1: Study Stages	17
Figure 2.3. 2: Clinical and implementation outcomes framework.....	18
Figure 2.3. 3: Study procedure flow chart	19
Figure 2.3. 4: Caregiver coaching session structure	21
Figure 3.2. 1: Intervention Adaptation Documented by Wiltsey-Stirman Framework....	30
Figure 3.3. 1: Average caregiver item scores for each subscale over 12 intervention sessions.....	32
Figure 3.3. 3: Caregiver acquisition of ESDM techniques across caregiver-child play activities (80%=implementation fidelity.....	34
Figure: 3.3. 4: Average non-specialist coaching item scores for each subscale over 12 intervention sessions	36
Figure: 3.3. 5: ECD Worker Average Coaching Fidelity Score per session across 12 weeks	38

List of Tables

Table 2.5. 1: Coaching Fidelity Scale.....	21
Table 2.5. 2: Caregiver Fidelity Scale.....	22
Table 3.1. 1: Children and caregiver demographics (n=4).....	26
Table 3.1. 2: Early Childhood Development (ECD) workers demographics (n=2).....	27
Table: 3.3. 2: Individual and average scores for caregiver fidelity rating items	33
Table: 3.3. 5: Individual and average scores on coaching fidelity rating items	37

Acknowledgements

I would to thank Dr. Lauren Franz and Dr. Petrus de Vries for providing me with the opportunity to be part of their important research program. I would like to give special thanks to everyone on the South African ESDM team for making my fieldwork experience very enjoyable, in particular Dr. Nokuthula Shabalala, Noleen Seris, and Marisa Viljoen. I am grateful to my thesis committee members, Dr. Melissa Watt, Dr. Joe Egger and Dr. Brandon Knettel, for their input on this work and for helping me get through difficult times. Finally, I would like to thank everyone from the education team at the Duke Global Health Institute for their guidance throughout this entire degree process.

1. Introduction

1.1 Autism Spectrum Disorder

Autism spectrum disorder (ASD), a lifelong neurodevelopmental disorder, is recognized by the World Health Organization as a growing global public health concern (World Health Organization, 2013) and may represent some of the greatest burden of disease among all conditions in children and adolescents. Globally, autism is estimated to affect 24.8 million people as of 2015 (Global Burden of Disease, 2015). In 2014, the World Health Organization (WHO) initiated a program called the “Comprehensive and Coordinated Effort for the Management of ASD” (World Health Organization, 2013b). This resolution is co-sponsored by more than fifty countries and supported by all WHO member states. The program calls for the “development, strengthening and implementation of national policies which align with the needs of persons with ASD and with evidence and best practice” (WHO, 2014). In 2018, the U.S. Centers for Disease Control and Prevention (CDC) released data on the prevalence of autism in the United States, which identified 1 in 59 children (1 in 37 boys and 1 in 151 girls) as having ASD (CDC, 2018). In the United States, the past two decades have seen a dramatic increase in the numbers of individuals receiving services from educational and developmental disabilities service agencies under the autism classification (Newschaffer, 2007).

1.2 Early Intervention for ASD

There is no known cure for ASD. However, functional, cognitive, and language improvements can be seen when children and families have access to evidence-based

early intervention, including family counseling and education. Such early detection and early intervention are particularly important within the first three years of life because they can reduce the severity of core ASD symptoms and result in significant long-term improvements in social skills, cognitive abilities, and adaptive behaviors (Dawson et al, 2010; Rogers et al, 2012; Estes et al., 2015). Early intervention can also be cost-effective. In the United States, the total annual cost associated with ASD has been estimated to approach \$250 billion (Lyall, 2017). Early intervention can decrease long term costs associated with special education services, sheltered employment and supported living (Cidav et al., 2017). With the rise in the number of children being diagnosed with ASD, coupled with the push toward earlier detection, there is a vital need to develop interventions that are appropriate for infants and toddlers and their families, which can begin immediately after diagnosis and support the needs of parents (National Research Council, 2001).

In low- and middle-income countries (LMICs), early intervention for ASD is severely challenged by the lack of highly-trained therapists to provide intervention to children who are in need of such services (de Vries, 2016). LMICs such as South Africa require early ASD intervention approaches that incorporate the local context (Guler et al., 2017) and involve non-specialist providers in delivery (Guler, de Vries, Seris, Shabalala, & Franz, 2017). Only by reflecting the local context and resources will early intervention models be sustainable in LMICs.

1.3 Naturalistic Developmental Behavioral Interventions and the Early Start Denver Model

Naturalistic developmental behavioral interventions (NDBIs) are a category of ASD intervention that are implemented under natural settings, involve shared control of the child-adult activity, and make use of naturally occurring opportunities for learning. In NDBIs, intervention therapists can use a variety of behavioral strategies to develop vital skills for children with ASD (Schreibman et al., 2015). In nearly all NDBIs, child developmental goals align with standardized assessment tools, which help guide the clinician in choosing developmentally appropriate treatment goals across child developmental domains.

The Early Start Denver Model (ESDM) (Schreibman et al., 2015) is an NDBI that was developed to provide early intervention for children with ASD who are 12 to 60 months of age. ESDM therapists complete a treatment-specific curriculum and assess children on a variety of measurable behaviors across developmental domains, which guides the development of specific goals for each child (Rogers et al., 2012). Several approaches come together to form the foundation of ESDM, specifically: 1) the Denver Model; 2) Rogers and Pennington's Model of Interpersonal Development in Autism; 3) The Social Motivation Hypothesis of Autism; and 4) Pivotal Response Training (PRT). The Denver Model was originally developed by Rogers and colleagues (Rogers and Lewis, 1989; Rogers et al., 1986; 2000) and encourages development in a variety of areas known to be affected in ASD, following sequences of development seen in children without developmental delays. The Model of Interpersonal Development in Autism supports the finding that early intensive behavioral intervention can subsequently

promote significant gains in cognitive, language, and social development. The Social Motivation Hypothesis of Autism focuses on social rewards to enhance a child's social attention and motivation for social interaction (Rogers and Lewis, 1989; Rogers et al., 1986; 2000). Lastly, PRT incorporates specific variables associated with motivation within a systematic teaching approach to increase communication, language, and play skills. Taken together, the ESDM is an evidence-based behavioral intervention that aims to improve social communication skills in children with ASD (Koegel et al., 1998; Vismara et al., 2009; Lei & Ventola, 2017).

Early detection of ASD, compared with evidence-based treatment models like ESDM can improve intellectual ability and adaptive behaviors, and decrease core ASD symptom severity and challenging behaviors (Dawson et al, 2010; Rogers et al, 2012; Estes et al., 2015). However, given the scarcity of specialist service providers in most LMICs, it is unlikely that, in the foreseeable future, there will be sufficient highly trained therapists to provide ESDM intervention directly to the children who need it (de Vries, 2016).

1.4 Caregiver Delivered Early ASD Intervention

One method for expanding the quality and availability of services for children with ASD has been imparting skills to parents (Bearss, Burrell, Stewart, & Scahill, 2015). The WHO mental health Gap Action Program (mhGAP) also states as a strong recommendation that caregiver education and skills training must be an essential component of ASD programming (World Health Organization, 2015).

There are several randomized controlled trials (RCTs) that have examined the effectiveness of NDBIs implemented by caregivers of young children. Caregivers can be effective at helping children to engage, communicate, and learn by embedding NDBI-informed intervention skills into interactive caregiving routines (Baranek et al. 2015; Carter et al. 2011; Green et al. 2015; Kasari et al. 2010; Rogers and Dawson 2010; Rogers et al. 2014; Schertz et al. 2013; Wetherby et al. 2014). The Parent Early Start Denver Model (P-ESDM) is an example of an NDBI that is implemented by a caregiver (Rogers et al., 2012). The P-ESDM model provides sensitive, responsive teaching focused on children's interests, emotional regulation capacity, and a developmental perspective of how skills and behaviors unfold for infant to preschool aged children (Rogers and Dawson 2010; Rogers et al. 2014). In a U.S. based study examining the feasibility of a short-term caregiver educational program using ESDM skills, all caregivers showed improvement in ESDM techniques used during caregiver-child interactions after receiving 5 or 6 weeks of 1-hour weekly sessions (Vismara et al, 2009). The caregiver tended to maintain the skill level for the rest of the treatment period and at the three-month follow up. Another pilot study by Rogers and colleagues in the U.S. tested a 12-week, low-intensity caregiver coaching P-ESDM intervention with seven symptomatic infants aged between 7–15 months (Rogers et al., 2014). The infants were followed from 9 months to 36 months, and their overall developmental rates and ASD symptoms were compared to control groups of infants also at high risk for ASD. The treatment group began as the most symptomatic and language delayed of the groups, but over the 18 to 36 months of follow up the treatment group demonstrated significantly

fewer autism symptoms than those children who developed ASD in control groups that did not receive the caregiver-led intervention (Rogers et al., 2014). The study demonstrated improvement in all caregiver performances across the 12 weeks of treatment, with intervention skills maintained across 36 weeks of follow-up, and high levels of caregiver satisfaction with the intervention (Rogers et al., 2014). A more recent study documented the effects of an enhanced version of P-ESDM, with additions that included motivational interviewing, multimodal learning tools and weekly 1.5-hour home visits (Rogers et al., 2019). The study revealed greater gains in caregiver interaction skills with the enhanced version compared to the original P-ESDM approach, as well as a significant relationship between caregiver change in interaction and rate of child improvement on developmental and ASD symptoms (Rogers et al., 2019).

The evidence demonstrates that caregiver delivered ASD interventions can be effective and achieve desired fidelity in high-resourced settings with proper training from specialists. But it is still unknown if having non-specialists conduct the coaching can achieve similar treatment outcomes in lower-resourced settings.

1.5 Non-specialist providers as caregiver coaches

For caregiver delivered interventions to be feasible and sustainable in LMICs, there is a need to involve non-specialists as the caregiver coaches. There is evidence that non-specialists can be effectively integrated into ASD intervention (Reichow et al., 2013). A meta-analysis of “psychosocial interventions delivered by non-specialist providers for children with intellectual disability and ASD” identified 18 studies that

effectively reduced ASD symptomatology among individuals with ‘lower-functioning’ ASD (Reichow et al., 2013). This meta-analysis defined “non-specialists” as “teacher, aide, parent, general practitioner, nurse practitioner, or local clinician”. However, among the 18 identified studies, only one was conducted in an LMIC. This study examined the effects of a home-based intervention for young children with intellectual disabilities in Vietnam (Shin et al., 2009). The researchers involved eleven local teachers who had experience working with children with disabilities to coach parents to work with their children during weekly home visits. After the three months of training sessions were completed, these teachers held one-hour sessions each week with parents to review previous homework assignments, and identify new teaching objectives based on the parents’ goals. After weekly visits from the non-specialists for six months, the intervention group made significant gains in adaptive behaviors, daily living skills and motor skills.

The review by Reichow and colleagues demonstrated that non-specialists who had some professional experience with children but no higher-level education on pediatric mental health can effectively provide treatment to children with developmental disorders after appropriate training from specialists in an LMIC setting. Similar methods may help other nations, including South Africa, to reduce the resource gap and make ASD intervention services more accessible and more affordable to ASD children and families in lower-resourced settings. However, the meta-analysis highlights that the term “non-specialists” has not been clearly defined, and it is unclear whether there may be differences in outcomes across the different groups (e.g., teachers and parents) currently

combined into the “non-specialist” category. In addition, delivering of non-specialist intervention in LMICs must be fit into the local context by adapting existing evidence-based interventions.

1.6 South African early ASD intervention landscape

According to the World Bank (World Bank, 2018), South Africa is the lowest ranked country in the world for income inequality, with the top 1% of South Africans owning 71 percent of the nation's wealth, while the bottom 60 percent of South Africans collectively control only 7 percent of the country's assets. Such disparities are evident in the South African healthcare system (Mayosi & Benatar, 2014). From a report from South Africa National Treasury, the annual healthcare expenditure was \$150 per capita in the public sector, which serves 84% of the population, compared to \$1500 per capita in the private sector, which serves 16% of the population (South African National Treasury, 2010). Furthermore, the national public health sector is staffed by only 30% of the nation’s doctors, with the majority of doctors working full-time in the private sector. The state hospitals in South Africa are affected by underfunding, mismanagement and neglect (Mayosi & Benatar, 2014; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009).

The Western Cape Province of South Africa is considered one of the better resourced regions of the country (Western Cape Economic Overview, 2010). In the Western Cape, if a parent, caregiver, or teacher suspects a young child may have ASD, they can be evaluated in a primary care setting and referred to a neurodevelopmental clinic affiliated with a tertiary hospital for a formal diagnosis (Guler et al., 2017). This process typically takes 9-18 months, but may be longer. After a child is diagnosed with

ASD, they would usually be referred for therapy and their name would be placed on the Western Cape Education Department Provincial ASD waiting list for placement in a Special Education School that has specialized autism services. In 2016, there were 940 children with ASD in Special Education Schools in the Western Cape Province and 744 children were waiting for placement, of which 646 were younger than 7 years of age (Pillay, Duncan, & Vries, 2017). In a recent review of children on the ASD waiting list, there was a 276% increase in the number of children with ASD on the waiting list between 2012 and 2016 (Pillay et al., 2017). Services are available in the private sector, but are expensive and vary in quality (Guler, de Vries, Seris, Shabalala, & Franz, 2017).

Interviews with relevant policy makers in the Western Cape have concluded that they have very limited knowledge of ASD and its impact on health systems and society (Franz et al., 2018). Fortunately, South Africa's National Integrated Early Childhood Development Policy acknowledges the importance of investing resources to support and promote early child development, and asserts the commitment of the South African government to provide a comprehensive package of ECD services to all young children by 2030. Importantly, South African caregivers themselves desire affordable early intervention where they have 'active voice' in shaping their child's treatment goals (Guler, de Vries, Seris, Shabalala, & Franz, 2017).

1.7 Adaptation and Fidelity

Most early ASD interventions, such as ESDM, have been developed in high income countries like the United States (Rogers et al., 2012). Intervention adaptations are

therefore necessary in order to ensure the original model is appropriate and feasible in a new environment. Guler and colleagues identified eight contextual factors South African caregivers consider important when developing an early ASD intervention: “culture, language, location of treatment, cost of treatment, type of service provider, support, parenting practices, and stigma” (Guler, de Vries, Seris, Shabalala, & Franz, 2017). Documentation of the local adaption of the caregiver coaching version of ESDM for the South African context is informed by an adaptation framework developed by Wiltsey-Stirman and colleagues (Wiltsey-Stirman et al., 2013).

Adaptation is “planned or purposeful changes to the design or delivery of an intervention,” and it can include each of the following: deletions or additions of program components; modifications of the components included; changes in the manner or intensity of program components; or cultural modifications required by local circumstances (Pérez, Van der Stuyft, Zabala, Castro, & Lefèvre, 2015). Adaptation may be needed to facilitate implementation and ensure sustainability (Aarons et al., 2012). Adaptation of interventions may be required for a new target population or a new intervention delivery setting (Wiltsey-Stirman et al., 2013; Brownson et al., 2012). The steps of intervention adaptation are also crucial as one needs to understand which components can be modified and which components should stay the same. Thus, core intervention elements (the essential and indispensable part) and adaptable intervention characteristics (adaptable elements, structures and system related to the intervention and organization into which it is being implemented) should be identified (Damschroder et al., 2009). Adaptation should retain the core components of the intervention while

modifying the “adaptable characteristics” to ensure the original intervention ‘fits’ with the new implementation environment. The CFIR (Consolidated Framework for Implementation Science) model provides guidance on adapting the intervention to fit the “outer setting” (e.g., resources, governmental policies), the “inner setting” (e.g., institutional networks, culture), and the “individuals involved” (e.g., knowledge level or language skills of local collaborators) (Damschroder et al., 2009).

One of the major challenges in scaling up evidence-based programs is the tension between adaptation and fidelity (Aarons et al., 2012). This “adaptation-fidelity” tension necessitates a better understanding of how to facilitate delivery of evidence-based programs with appropriate adherence to the original intervention, while allowing for important contextual adaptations that do not interfere with core elements of the original intervention designed (Marsiglia et al., 2015).

Fidelity of intervention delivery is the degree to which programs are implemented as intended by program developers. Fidelity is important because it can moderate the effect of an intervention on targeted health outcomes (Carroll et al., 2007; Brownson, Colditz, & Proctor, 2012). Fidelity represents the quality and integrity of the intervention as conceived by intervention developers (Brownson, Colditz, & Proctor, 2012). Achievement of high implementation fidelity is one of the best ways of replicating the success with interventions achieved by original research (Carroll et al., 2007). If programs are implemented with fidelity to the original model, this increase the chances that the behavior change mechanisms that made the original model effective will be preserved (Arthur & Blitz, 2000). If some specific components of the original

intervention plan are omitted or not implemented as originally designed, it is possible that the omitted component could be the mechanism that is affecting much of the change in behavior, resulting in a loss of program effects (Mihalic, 2002). The concern of maintaining intervention fidelity is of particular importance when an adapted intervention approach is implemented in a different environment (Breitenstein et al., 2010).

1.8 Study Aims

Autism is increasingly recognized as a key public health challenge across the globe, including in lower-resourced settings such as South Africa (Franz, Chambers, von Isenburg, & de Vries, 2017). In order to respond to this challenge, there is a need to develop and evaluate cost-effective methods to address the needs of children and families affected by ASD (Payakachat, Tilford, Kovacs, & Kuhlthau, 2012). Involving non-specialists to coach caregivers to deliver early ASD intervention strategies to their young children may help address the global ASD treatment gap. These non-specialist intervention models need to be evaluated to ascertain whether they can remain effective while being relevant to the local context (Guler, de Vries, Seris, Shabalala, & Franz, 2017).

The long-term goal of the main ESDM research program in South Africa is to advance understanding of the efficacy of caregiver delivered early autism interventions coached by non-specialists in lower-resourced settings. This pre-pilot study had three specific aims: 1) Document adaptations made to a caregiver coaching approach, informed by ESDM principles and delivered by non-specialist providers in South Africa; 2)

Examine non-specialist coaching fidelity; and 3) Examine the fidelity of caregiver implementation of ESDM across 12 weeks of intervention sessions.

2. Methods

Overview

Data for this study are drawn from the pre-pilot phase of a larger study, funded by the National Institute of Mental Health. The parent study aims to adapt the caregiver coaching version of the Early Start Denver Model (ESDM) for implementation by non-specialists in South Africa, and includes both implementation science and clinical outcomes in a hybrid type 1 effectiveness design (Curran, Bauer, Mittman, Pyne, & Stetler, 2012). This pre-pilot study primarily aimed to assess the feasibility of the intervention training and supervision structure, with a focus on fidelity. Participants in the pre-pilot included 2 caregiver-child dyads with ASD, and 2 non-specialist ECD workers who provided the caregiver coaching. Fidelity was tracked for both non-coaches and caregivers to see how they performed in ESDM skills and the delivery of the intervention across 12 weeks.

Ethical clearance for the study was obtained from the University of Cape Town Human Research Ethics Council (HREC) (HREC 039/2015), Duke University Institutional Review Board (IRB) (IRB Pro00064533), and the Western Cape Education Department. Prior to data collection, the research was explained to each participant by study staff and written informed consent was provided. Study assessments and intervention sessions were all conducted in a private space in local autism schools. Caregiver participants received ZAR100 (approximately US\$7) to cover travel expenses

at each assessment and intervention session.

2.1 Setting

South Africa is the southernmost country in Africa, it is composed of nine provinces with a total population of around 57 million. The Western Cape Province, situated in the southwestern part of the country, is the fourth largest of the nine provinces and has an area of 129,449 square kilometers. It is the third most populated province with an estimated 6.6 million inhabitants in 2018 (STATS SA, 2018). Cape Town is the second most populous city in South Africa and is the provincial capital of the Western Cape. In 2018, Cape Town had an estimated population of 3.78 million. Cape Town is also one of the most multicultural cities in the world (Cape Town Population, 2018). South Africa has eleven official languages. From a census in 2011, 50% of the population in Western Cape's first language was Afrikaans, 20% was English, and 25% was isiXhosa. (City of Cape Town, 2011).

2.2 Participants

Study participants included two children-caregiver dyads, and two non-specialist ECD workers who delivered the caregiver coaching. Children-caregiver dyads were eligible for participation if they met the following criteria: 1) child was between 18 and 72 months old; 2) child had a diagnosis of ASD based on DSM-5 criteria; 3) caretaker speaks isiXhosa, Afrikaans or English; and 4) family lives within an area served by the Red Cross Neurodevelopmental clinic. Child-specific exclusion criteria were: 1) a neurodevelopmental disorder of known genetic etiology (e.g. Downs syndrome); 2)

significant sensory or motor impairment (e.g. cerebral palsy); 3) major physical problems; 4) uncontrolled seizures; 5) IQ below 35 as measured by mean age equivalence score on the Griffiths Scales of Mental Development; and 6) a caregiver who was unable to attend 3 assessments and 12, 1-hour, weekly consecutive intervention sessions. Eligible caregivers and children were chosen from local ASD school that had collaborated with the local ASD research facility. They were then asked to come in to the research facility for the pre-intervention baseline assessment and demographics questionnaires conducted by researchers.

Inclusion criteria for the ECD workers were that they needed to be employed by the Department of Education and work with local ASD schools; they needed to attend a four-day training on caregiver coaching and ESDM strategies prior to the 12 weeks of intervention sessions; After the pre-study training, the ASD school supervisors and the researchers identified the ECD worker and the caregiver-child dyad that would finally join the study.

2.3 Study Design

Figure 2.3.1 demonstrates different stages of the larger study in which this thesis is based. The parent study began with identifying contextual factors relevant to the South African context and tailoring the original caregiver coaching ESDM intervention to the South African context. Next, the researchers trained local non-specialist ECD workers on caregiver coaching techniques and ESDM concepts. In the current pre-pilot study (the phase is marked with asterisk), 2 caregiver-child dyads were coached in ESDM strategies by non-specialist ECD workers for 12, 1-hour sessions. As of March, 2019, participants

are currently being prepared to enroll in the larger pilot study.

Figure 2.3.1

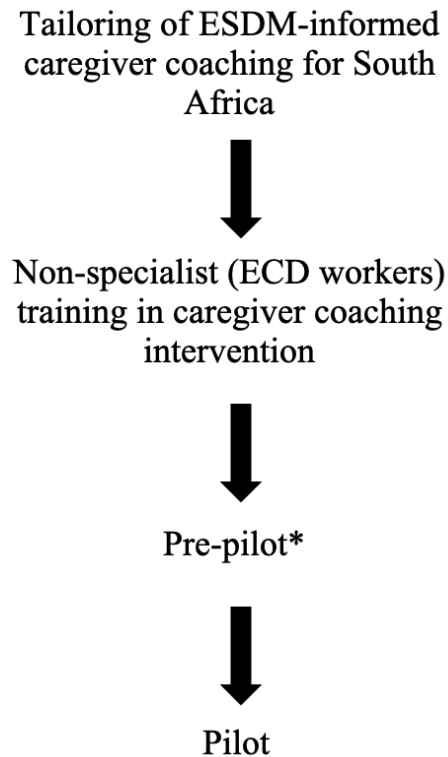


Figure 2.3. 1: Study Stages

Across both the pre-pilot and pilot phases of the study, clinical and implementation outcomes have been collected (Figure 2.3.2). Clinical outcomes include measures of child social communication, caregiver stress and sense of competence. Implementation outcomes include fidelity (non-specialist caregiver coaching fidelity and caregiver implementation fidelity); acceptability, appropriateness and feasibility of the adapted intervention; and barriers and facilitators of intervention implementation. The

data presented in this thesis focus on the “fidelity” data under the implementation outcomes category.

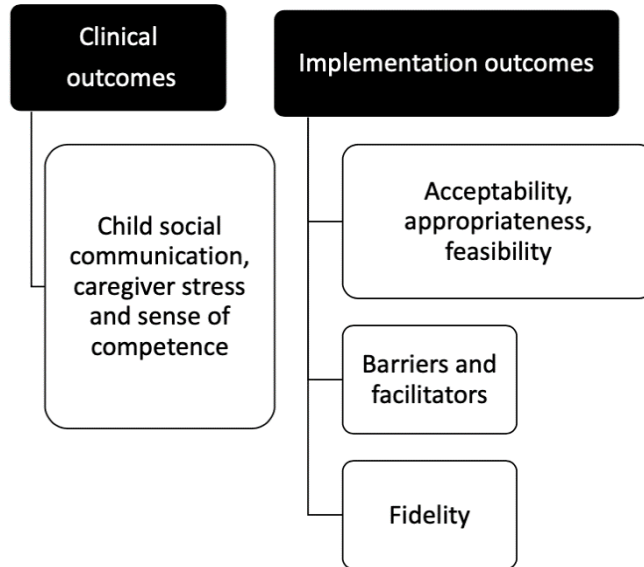


Figure 2.3. 2: Clinical and implementation outcomes framework

2.3.1 Procedures and Data Collection

Figure 2.3.3 illustrates the procedure flow chart of this pre-pilot study, starting from the training for ECD workers prior to the intervention sessions up to the final data analysis step. To begin with, two ECD workers and their supervisors from autism schools in the Western Cape Province were recruited to participate in a four-day caregiver-coaching training on the caregiver led ESDM intervention (C-ESDM) (Rogers et al., 2017). After the training, partner schools each identified one caregiver-child dyad who met study inclusion/exclusion criteria and invited them to participate in the study. Following a comprehensive baseline assessment, the caregiver-child dyads received 12

sessions of caregiver coaching by the ECD workers. Video-recording equipment was used to capture assessments and intervention sessions to allow for coding. Fidelity of caregiver implementation of ESDM and the fidelity of ECD worker caregiver coaching were independently rated from 12 video-recorded intervention sessions by a certified ESDM therapist and an ESDM trainer.

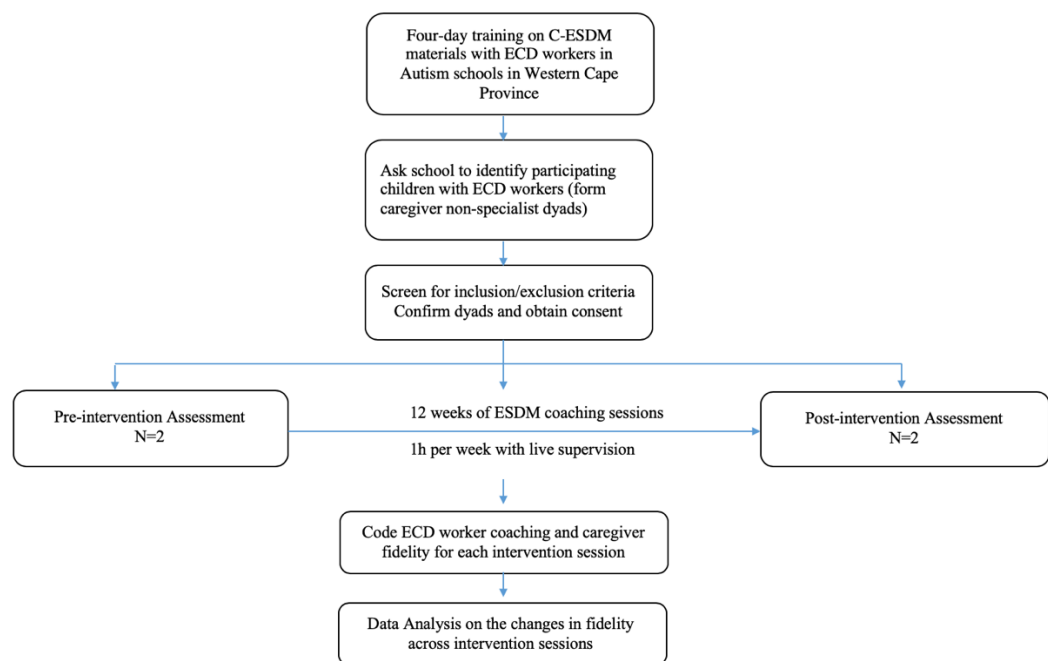


Figure 2.3. 3: Study procedure flow chart

Figure 2.3.4 details the session structure for the twelve 1-hour intervention sessions of caregiver coaching. During each session, the new skill or topic was introduced by a Community ESDM video, “Help is in your hands” (Rogers et al., 2017).

The videos serve as tutorials as a part of ECD worker's coaching sessions by teaching necessary ESDM skills. Caregivers can also watch the videos in advance at home to prepare for the session, as they were given all videos before the twelve-week intervention started. After learning the theoretical knowledge from the videos, the caregiver started to practice these skills during interactive activity with their children while the ECD workers sat on the side and provided real-time coaching. During the coaching process, the ECD worker provided the opportunity for the caregiver to reflect on the caregiver-child interaction. During this reflection, the ECD worker helped the caregiver tie their child's behaviors to their own behaviors during the activity. At the end of each coaching session, the ECD worker encouraged the caregiver to think about how the session skill could be generalized to various activities of daily life, such as bathing, mealtime and during chores.

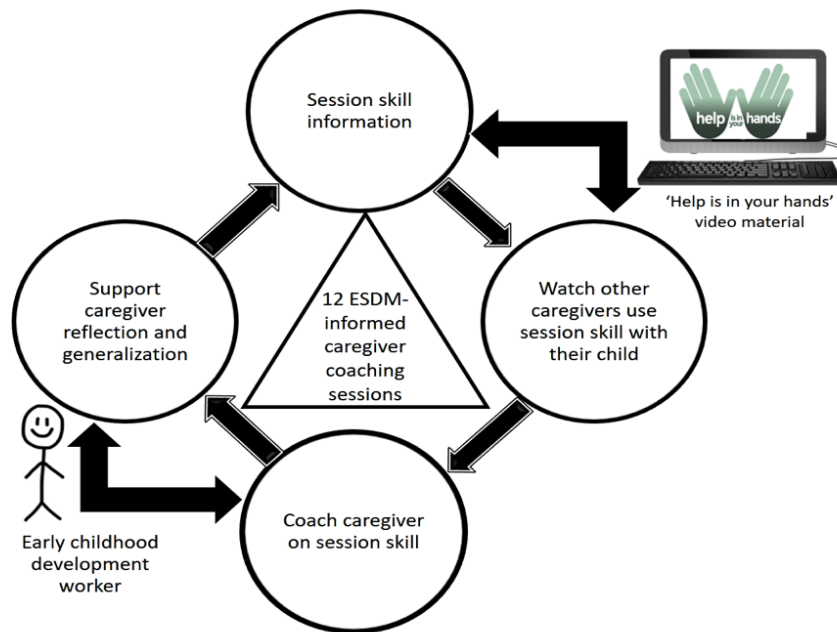


Figure 2.3. 4: Caregiver coaching session structure

2.4 Adaptation

In order to fit the program to the local context of South Africa, modifications were made to the intervention prior to the initial encounter with participants. This study used a framework developed by Wiltsey-Stirman et al. to document the adaptations made to the original ESDM intervention (Wiltsey-Stirman et al., 2013). The Wiltsey-Stirman framework identifies five types of modifications, including 1) By whom are modifications made? 2) What is modified based on program content, context, training and evaluation? 3) At what level of delivery are modifications made? 4) What are the contextual modifications based on format, setting, personnel and population? 5) The fifth question is what are the nature of the content modification used to adapt to the original program? (Wiltsey-Stirman et al., 2013).

2.5 Fidelity assessment tools

Fidelity of intervention delivery, meaning how closely programs are implemented as intended by program developers, is important because it may be a moderator of intervention efficacy (Carroll et al., 2007; Brownson, Colditz, & Proctor, 2012). Because of the numerous contextual adaptations made to the caregiver coaching intervention, fidelity was an important implementation outcome to monitor in this pre-pilot.

Researchers evaluated fidelity scores based on recorded videos of all sessions across twelve weeks. Two fidelity-rating tools were utilized in this study: (1) ESDM Coaching Fidelity Rating System and (2) P-ESDM Caregiver Fidelity Rating System.

2.5.1 Coaching Fidelity Rating System

The ESDM Coaching Fidelity Rating System provides a method for assessing whether the non-specialist ECD worker is coaching P-ESDM techniques at fidelity. The fidelity assessment tool evaluates 14 adult coaching behaviors during the caregiver coaching sessions. Items are individually rated with a Likert-type rating scale with values that vary from 1 to 4, with higher scores reflecting a greater degree of fidelity. Items A to F follow the timeline of one intervention session and items G to M are coaching characteristics being evaluated across the entire session (Table 2.5.1).

Coaching Fidelity Scale		
Item A-F (Small sections following the timeline of one full session)		
Rating Item name	Description	Full score performance description
Item A. Greeting and check-in	It is the phase when parents share the progress and	The coach should show interest, listen actively, follow up as needed and acknowledge parent's efforts over the

	challenges from the last session.	week. This should be a smooth transition into the parent-child activity.
Item B. Warm up activity	It is a phase for the coaches to observe and evaluate parent-child interaction based on what was discussed and practiced in the last session.	The coach allows the activity to occur without interruptions while the parent provides some evaluation of the activity at the coach's invitation. The coach should provide constructive comments concerning parent's behaviors and child response.
Item C. Introduction of the topic	It is a phase when the coach sets the main topic for the sessions and introduce the events that will happen in the session.	The coach should clearly define the topic, ties the topic to parent's goal for the child, ties the new topic into discussion in previous sessions with parent, applies multimodal strategies to best fit the learning needs of the parent. The coach should also solicit parent input to assess understand and demonstrate sensitivity to parent and child's cultural beliefs.
Item D. Coaching on activity 1	Two phases focusing on coach's skills to support parent attention and success at using the topic skills.	The coach should be able to adjust techniques according to parent's learning styles, understanding level, child goals and increasing success. The coach should provide enough support for the parents to successfully carry out the new skills and achieve the child target and invite the parent to reflect on experience and evaluate key interactions using open-ended questions and active listening
Item E. Coaching on activity 2		
Item F. Closing	It is the time when the coach and the parent carry out a balanced, interactive and reflective discussion	The coach addresses topics still open, generalization of the techniques across child's daily activities and ends the session smoothly
Item G-M Coaching characteristics that cover the entire session		
Rating item name	Full score performance description	
Item G. Collaborative	The coach collaborates with the parent to establish and reach common goals together. Both coach and the parent share expertise, convey recognition and respect each other's knowledge and abilities, ask questions, listens and summarizes each other's responses to identify goals, topics and concerns.	
Item H. Reflective	The coach to reflect on 1) what the coach observed, 2) the relationship between learning goals and observed actions, 3) effects of parent behavior and child behavior, 4) emotional expressions occurring and provide clear thoughts from reflection to action and support the parent's reflection and evaluation process	
Item I. Non-judgmental	It requires the coach to use descriptive rather than evaluative or judgmental language to point out relations between parent actions and child behaviors.	
Item J. Conversational and Reciprocal	It requires the coach to interact with the parent as a partner and be sensitive about the timing of conversation, staying on-topic and sharing control	
Item K. Ethical conduct	It requires the coach maintains appropriate professional behavior and ethical conduct throughout the session	

Item L. Organization and management of session	It requires the coach to well organize the session both temporally and physically. The activities flow according to the plan and if the plan is derailed the coach needs to develop a new organization and make sure the essential parts are not lost
Item M. Managing parental implementation difficulties	It requires no conflict in the session or whenever there is a conflict the coach needs to demonstrate awareness of underlying issues, invite parent to share viewpoint and listen to their views, finds anew solution for the conflict and in the end make this process strengthens the parent-coaching bonding and refocuses all on child intervention needs.

Table 2.5.1 Coaching Fidelity Scale Rating Item Description

See the Appendix for all rating items and their matching full score performance description, directly extracted from the official guide.

2.5.2 Caregiver Fidelity Rating System

The P-ESDM Caregiver Fidelity Scale provides a method for assessing the fidelity with which a caregiver is using ESDM principles in a learning interaction with a young child. The scale was developed for rating videotapes of activities where parents and children are together during the intervention session while the ECD worker is observing on the side. The rating scale includes ratings of performance from 1 to 5. There are thirteen items included in this scale and they do not follow a specific timeline of the intervention (Table 2.5.2).

Caregiver Fidelity Scale	
Rating Item Name	Full Score Performance Description
Item A. Management of child attention	It requires the parent to grasp child’s attention at the beginning of the intervention session, maximize it, sustain it through teaching activities and make adjustments through multiple practice opportunities. By doing this the child can show coordinated and alternating attention to parent and teaching activities.
Item B. Antecedents, Behavior, and Consequences: “ABC” Format	It requires the parent to use a clear ABC format during the intervention session and parents should deliver multiple teaching trials during the activity on the average of every 10-20 seconds. In addition, the number of repetitions for each skill is

	appropriate and well matched to the child's learning needs.
Item C. Instructional techniques and application	It requires the parent to consistently apply prompting and fading reinforcement techniques toward target skills (Prompting and fading). The child shall flow through the teaching sequences smoothly under the guidance of the parent (chaining) and child makes very few errors because the parent handled the tasks well (management of errors).
Item D. Parent ability to modulate child affect and arousal	It requires the child to show no problems with arousal or affect during the session. Or even when the child shows some level of affect and arousal problems the caregiver would show skills to optimize child's state and result in successful learning activities with many learning opportunities and engaged child.
Item E. Management of unwanted behaviors	It requires the caregiver to demonstrate understanding of the function of behavior and use appropriate techniques to elicit more appropriate behaviors.
Item F. Quality of dyadic engagement	It requires caregiver and child to act in a coordinated fashion. At its best, the child is aware of the caregiver's activities and regard parent as an interactive partner. Reciprocity and social engagement permeate the teaching activity and caregiver should incorporate reciprocal dyadic engagement into teaching.
Item G. Parent optimizes child motivation for participating in the activity	The child in an optimal session should demonstrate high motivation and high interest in the activity. The child should engage repeatedly in the learning activities, respond consistently to parent instructions and initiate communicative behaviors that request more learning activities. The parent should be able to make adjustments and create many child choices to maintain high motivation throughout the activity.
Item H. Parent use of positive affect	Caregiver should display rich genuine and positive affect throughout the session matched by child positive affect. The positive affect should be well matched to child's needs and capacities, do not over arouse the child and serves teaching well.
Item I. Parent sensitivity and responsivity to child communicative cues	Caregiver need to demonstrate optimal sensitivity and responsivity to child cues. The parent should read the child very well and make every effort to interpret the child's meaning.
Item J. Multiple and varied communicative opportunities occur in the activity	It requires the caregiver to incorporate different communication functions throughout the session as specified in objectives including opportunities to request, protest comment, ask for help, greet, name, expand et al. Different techniques should also be used in objective-oriented activities so that child communication can occur repetitively approximately every 10 seconds.
Item K. Appropriateness of parent language for child's language level	Caregiver need to make sure his or her language is always developmentally and pragmatically appropriate for the child's verbal and non-verbal communicative capacity.
Item L. Joint Activity Structure and elaboration	This item includes a four-part joint activity. 1) Child chooses the activity and parent to set up the theme, 2) both child and parent co-construct the activity, 3) elaboration to encourage the use of actions and materials and 4) an ending that fits with the timeline and make sure the child is well-supported through the transition to the next

	activity. A high scoring parent need to provide an optimal four-part joint activity including a well-developed closure.
Item M. Transition between activities	Parent should be able to handle child’s shift of interest and the appropriate timing to move from one activity to another so that the child’s learning time in both activities is maximized and the down time to flow from one activity to another is minimized.

Table 2.5.2 Caregiver Fidelity Scale Rating Items Description

See the Appendix for a list of all the rating items and their matching full score performance descriptions, extracted from the official guide.

2.6 Data Analysis

Fidelity scores were imported into Excel (Microsoft Excel for Mac Version 16.19) for each of the 12 coaching sessions for the 2 caregiver-child dyads. Graphs and tables were created for each rating scale (13 items in the Caregiver Fidelity Scale and 13 items in the Coaching Fidelity Scale). The graph illustrates the average item score for each subscale over all intervention sessions for both caregivers. The table lists all rating items and their scores, separately for each caregiver. The rating items were displayed in order from lowest to highest average item score for both caregivers, standard deviations are also presented next to the average scores to indicate whether the fidelity scores are consistent or not.

Scoring 80% of the total score on rating scale items was considered as having “fidelity”. For example, in the Coaching Fidelity Scale where the full score is 4 out of 4, if the coach scored 3.2 or higher on the average fidelity scores across all sessions for all rating items, then the coach can be described as reaching adequate fidelity in his or her

coaching sessions. The Caregiver Fidelity Scale used a cut-off of 4 (out of possible 5) for fidelity on caregiver coaching intervention sessions. Caregiver acquisition of ESDM techniques across caregiver-child play activities was compared by graphically displaying each session of the caregiver's score percentage on caregiver fidelity rating items to the 80% fidelity line to visually display if the two caregivers reached fidelity in each session across the twelve intervention sessions.

3. Results

3.1 Participant Demographics

The demographic information on the two children and their caregivers who participated in the study is presented in Table 3.1.1. The ADOS-2 Comparison Score indicates the level of autism spectrum-related symptoms compared to children with ASD who are the same age and have similar language skills (Lord et al., 2000). Child 1 completed an ADOS-2 module 1, which indicates he used no words or only single words. Child 2 completed an ADOS-2 module 2, which indicates he used phrase speech (non-echoed three-word utterances that sometimes involve a verb and are spontaneous meaningful word combinations, but not at fluent speech yet). Demographic information on the two ECD workers who participated in the study is presented in Table 3.1.2.

	Child 1	Child 2
Gender	Male	Male
Ethnicity	Coloured*	Indian
Age at baseline assessment (Months)	61	61
First language	English	English
ADOS-2 (Module / Comparison score)	Module 1 Comparison score: 7	Module 2 Comparison score: 6
	Caregiver 1	Caregiver 2
Relation to Child	Father	Mother
Age (Years)	33	36
Ethnicity	Coloured	Coloured
Level of Education	Tertiary	Grade 12
Employment status	Employed, part-time	Not currently working

Table 3.1. 1: Children and caregiver demographics (n=4)

*Coloured: (Afrikaans: Kaapse Kleurling) are an ethnic group in southern Africa. In the Western Cape, there is a distinctive Cape Coloured and affiliated Cape Malay culture. In other parts of Southern Africa, people classified as Coloured were usually the descendants of individuals from two distinct ethnicities.

	ECD Worker 1	ECD Worker 2
Gender	Female	Female
Ethnicity	Coloured	African
Level of Education	Certificate/Grade 12	Certificate
First Language	English	isiXhosa

Table 3.1. 2: Early Childhood Development (ECD) workers demographics (n=2)

3.2 Adaptation of P-ESDM

The Wiltsey-Stirman framework was used to document adaptation of P-ESDM for the South African context (Wiltsey-Stirman et al., 2013). Figure 3.2.1 illustrates adaptations to the intervention according to the domains of the framework.

Modifications to the intervention were made by a coalition of stakeholders who actively participated in the decision-making process through multiple meetings where training documents were reviewed and edited. Stakeholders included the study principal investigator, who is a certified trainer in the intervention and has expertise in implementation science, as well as three local South African clinical practitioners who are certified therapists in the intervention. The content of the intervention was adapted in several aspects. Firstly, Caregiver-ESDM coaching materials were added. These materials included C-ESDM techniques used to train the ECD workers, and techniques used in caregiver coaching sessions to explain the session topic to the caregiver. Secondly, the context of where the intervention was implemented was also modified. The intervention was originally developed in the United States, and it was now being

implemented in South Africa, to be implemented in ASD schools in the Western Cape Province. Finally, since the study is still in its pre-pilot phase where we still need some on-site surveillance; Modifications were made to the training and evaluation/supervision approach. C-ESDM materials were used to train non-specialist ECD workers and live in-session supervision was provided for ECD workers which was not in the original intervention.

Adaptations were also made at different levels of intervention delivery. There are seven levels of delivery provided in the Wiltsey-Stirman framework and two were used in this study. The first level is practitioner level. In this study, non-specialist ECD workers coached caregivers instead of having specialized trainers coach the caregivers. By doing this, the individual practitioners who deliver the intervention changed to reflect the lack of specialist providers in South Africa. The second level we included in this study is the unit level. Unit level means that a modification is made by all of the facilitators within a unit such as a certain clinic, a certain grade level, or a certain department. For this study, the intervention was delivered in local autism schools that collaborated with ECD workers and were capable of providing early intervention instead of academic research facilities.

Context is about “setting the stage” for an intervention to be delivered and contextual modifications focus on the actual delivery of the intervention content. There are four categories included in this category. The first context modification is format, or the changes made to the channel of treatment delivery. The format of this intervention was modified by adding C-ESDM training sessions to the original P-ESDM materials so

that a group teaching activity could be added to the one-on-one intervention sessions. The second context modification is setting. In this study setting was modified by introducing ECD caregiver coaching sessions in local ASD schools instead of research facilities. The third context modification category is personnel. The adapted intervention is delivered by non-specialist ECD workers instead of highly-trained professionals. The final context modification is the population. The intervention was adapted to be implemented to a multi-lingual and multi-cultural South African community, which is different than the targeted population originally intended.

Lastly, several content modifications were undertaken. The Wiltsey-Stirman framework identifies 12 types of content modifications: tailoring, adding, removing, shortening, lengthening, substituting, re-ordering, integrating approaches with intervention, integrating intervention with approach, repeating, loosening and departing. The adaptation in this study used two of these content modifications: adding and tailoring. C-ESDM materials were added to the original intervention to train ECD workers and introduce the session topic to caregivers. The intervention's supervision design was also tailored to meet the needs of the ECD workers. As this was the first time both ECD workers were coaching caregivers on early intervention techniques, live supervision was provided during the 12 intervention sessions by a certified ESDM therapist. This supervision was based in individual needs and decreased over time as the ECD worker demonstrated greater competence in intervention delivery.

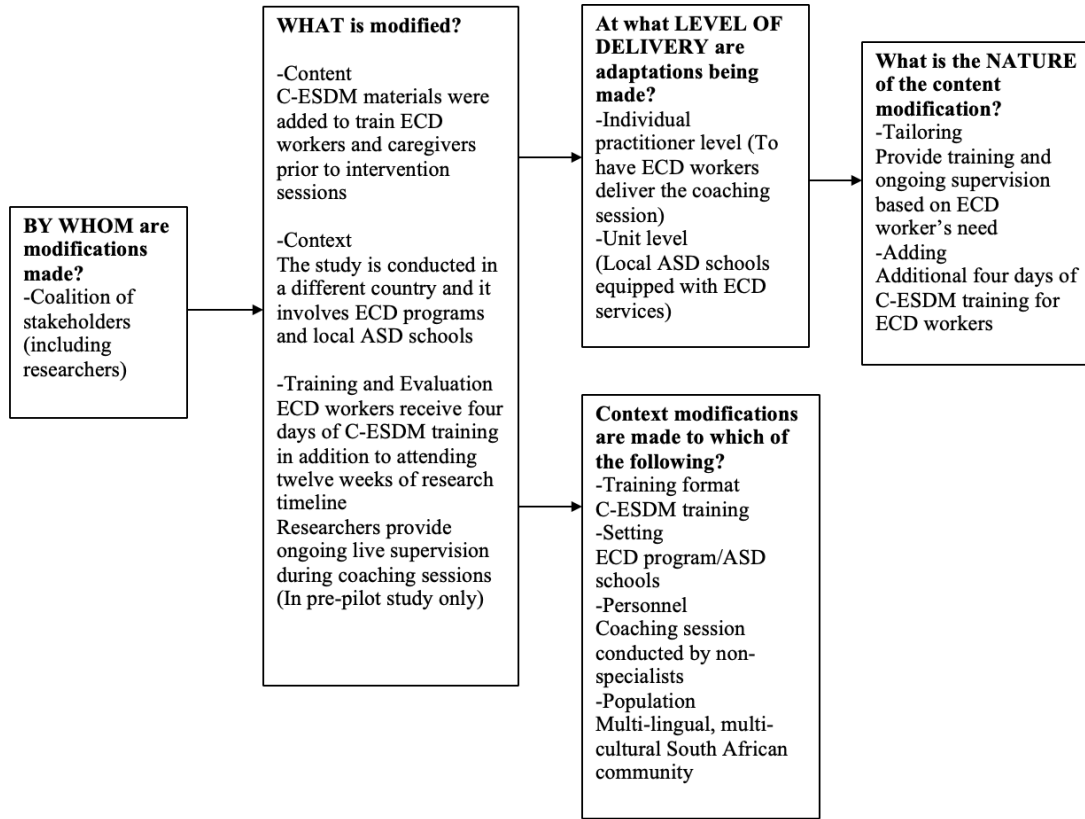


Figure 3.2. 1: Intervention Adaptation Documented by Wiltsey-Stirman Framework

3.3 Fidelity

Fidelity is a way of assessing whether an intervention is being implemented in the way intended by the intervention developers (Carroll et al., 2007). Maintaining high levels of implementation fidelity is crucial to maintaining the rigor and reproducibility of results from original interventions trials (Mihalic, 2004). In this study, adaptations to the original P-ESDM intervention (described above) were made to increase the ‘fit’ of this intervention with the South African context. After the adaptations were made, the fidelity of the adapted intervention during the pre-pilot was measured by the Caregiver Fidelity Scale and Coaching Fidelity Scale.

3.3.1 Caregiver Fidelity Scale Scores

Figure 3.3.1 demonstrates the average score on the Caregiver Fidelity Scale, rating 12 items across 12 intervention sessions. The x-axis lists the twelve scale items from A to L. The blue and orange bars for each item represent the two caregivers who participated in the study with their child, with the blue bar indicating caregiver 1 and the orange bar indicating caregiver 2. The y-axis indicates the scoring range of individual caregiver fidelity items (1 to 5 as 1 is the lowest rating and 5 is the highest). The graph hides part of the y-axis (0-2) where no ratings fell to visually better present the bar differences. We can observe from the graph that “parent ability to modulate child affect and arousal” and “management of unwanted behaviors” scored the highest for both Caregiver 1 (4.72, 4.92) and Caregiver 2 (5, 5), with score on the other ten items ranging from 2.5 to 4.55 for both caregivers. Overall, Caregiver 2 tended to have higher scores than Caregiver 1.

Figure: 3.3. 1: Average caregiver item scores for each subscale over 12 intervention sessions

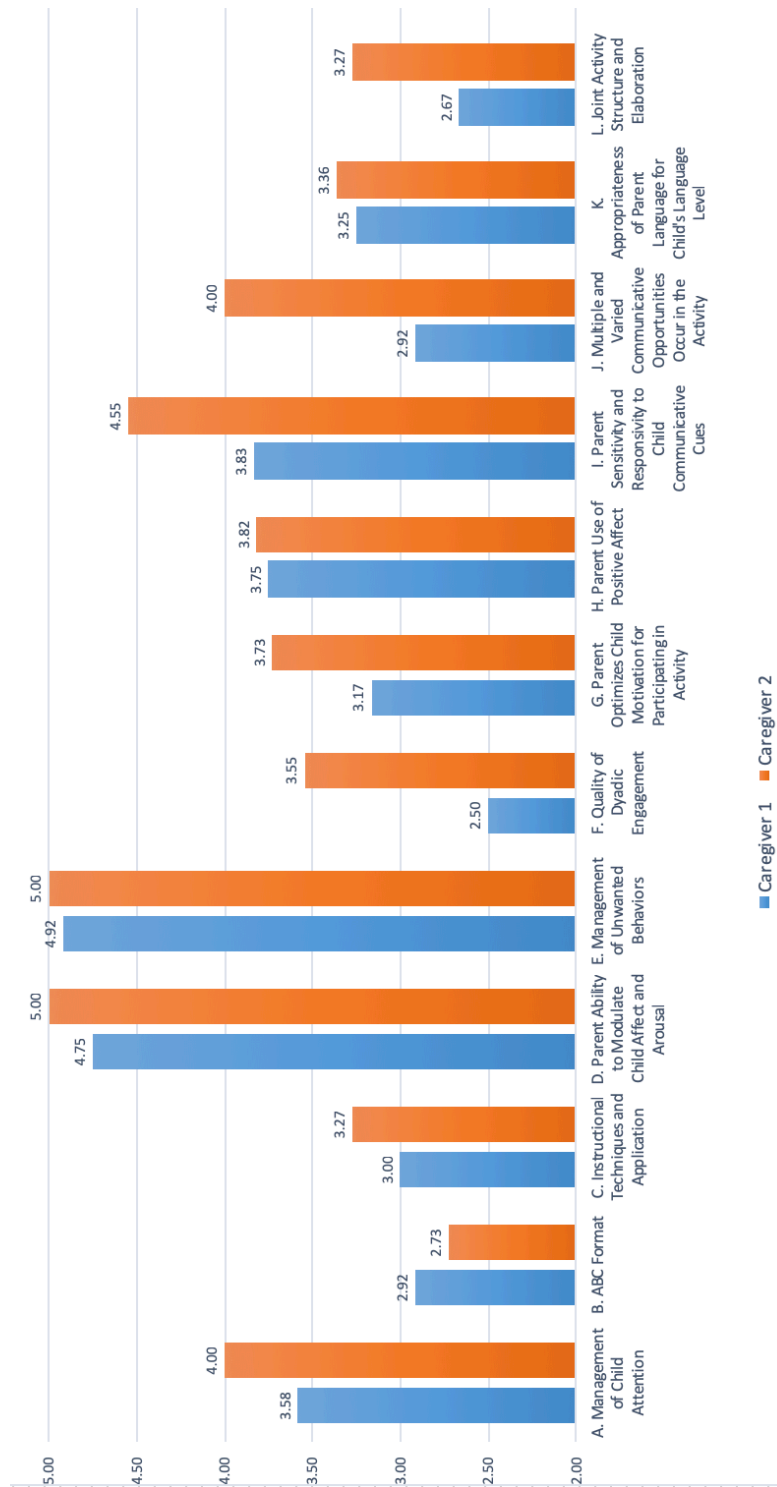


Table 3.3.2 presents the same data, with items arranged from lowest to highest score and the combined average item score across 12 intervention sessions presented for both caregivers. The bottom row of the table shows the average caregiver fidelity item score across all sessions. Caregiver 1 had an average item score of 3.45 out of 5 across 12 sessions (SD=0.60), and Caregiver 2 had an average item score of 3.86 out of 5 (SD=0.51), and the total average for both caregivers across all twelve sessions are 3.65 out of 5. The lowest five caregiver fidelity items were ABC format, joint activity structure and elaboration, quality of dyadic engagement, instructional techniques and application, and appropriateness of parent language for child's language level (see Table 2.5.2 for more detail on these components).

Caregiver Fidelity Rating Items	Participants	Caregiver 1	Caregiver 2	Average Item Score (Lowest to Highest)
ABC Format		2.92	2.73	2.82
Joint Activity Structure and Elaboration		2.67	3.27	2.97
Quality of Dyadic Engagement		2.50	3.55	3.02
Instructional Techniques and Application		3.00	3.27	3.14
Appropriateness of Parent Language for Child's Language Level		3.25	3.36	3.31
Parent Optimizes Child Motivation for Participating in Activity		3.17	3.73	3.45
Multiple and Varied Communicative Opportunities Occur in the Activity		2.92	4.00	3.46
Parent Use of Positive Affect		3.75	3.82	3.78
Management of Child Attention		3.58	4.00	3.79
Parent Sensitivity and Responsivity to Child Communicative Cues		3.83	4.55	4.19
Parent Ability to Modulate Child Affect and Arousal		4.75	5.00	4.88
Management of Unwanted Behaviors		4.92	5.00	4.96

Average fidelity score for all rating items	3.44	3.86	3.65
--	-------------	-------------	-------------

Table: 3.3. 2: Individual and average scores for caregiver fidelity rating items

Figure 3.3.3 illustrates caregiver acquisition of ESDM techniques (mean score of all Caregiver Fidelity items) over 12 intervention sessions. The x-axis of this graph shows time points for the 12 intervention sessions. Fidelity data from Caregiver 1 and Caregiver 2 are represented using blue and orange lines, respectively, on the graph. The y-axis of the graph presents the fidelity percentage, ranging from 0-100%. The graph hides part of y-axis (0-30%) where no ratings fell to visually better present the line fluctuation. Each percentage value is calculated by dividing the raw data by five and multiplying by 100. For example, if the raw data was 4.5, then calculation is conducted: $\frac{4.5}{5} \times 100 = 90\%$, so 4.5 would be marked as 90% on this graph. The dashed line is presented on the graph to mark the 80% fidelity cutoff in order to give clear visualization of whether caregiver ESDM intervention techniques approached fidelity in each of the 12 sessions. The graph shows that caregiver 1 came close to fidelity (above 70% but lower than 80%) in sessions 3, 4, 5, 9, 10 and was at fidelity in session 7. Caregiver 2 achieved or surpassed 80% fidelity in sessions 4, 6, 8 and 11.

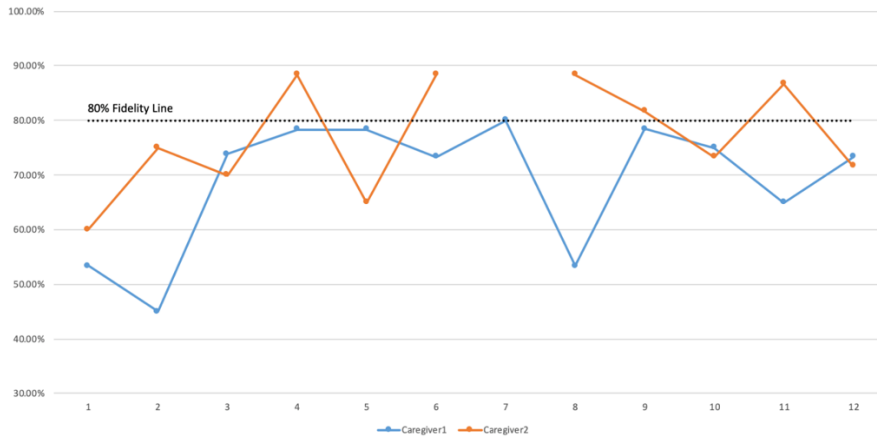


Figure: 3.3. 3: Caregiver acquisition of ESDM techniques across caregiver-child play activities (80%=implementation fidelity)

*The video recording equipment malfunctioned during session 7 for caregiver 2, therefore data from that session are missing

3.3.2 Coaching Fidelity Scale Scores

Figure 3.3.4 demonstrates the average ECD worker coaching fidelity score for each item over 12 intervention sessions. The x-axis of the graph lists the thirteen items on the Coaching Fidelity Scale, the blue and orange bars represent the average item score across the two caregivers for each of the 12 intervention sessions. The green bar represents ECD worker 1, and the yellow bar represents ECD worker 2. Item C “Introduction of the topic” was not included because the session skill was taught to the caregiver with “Help is in Your Hands” video materials. The y-axis shows the item scores of the Coaching Fidelity Scale, which ranges from 1 to 4. The graph hides part of the y-axis (0-2) where no scores fell to visually better present the bar differences. The graph indicates that ECD worker 2 had overall higher average item scores than ECD worker 1, which suggests greater competence in implementing the study caregiver coaching approach.

Figure 3.3. 4: Average non-specialist coaching item scores for each subscale over 12 intervention sessions

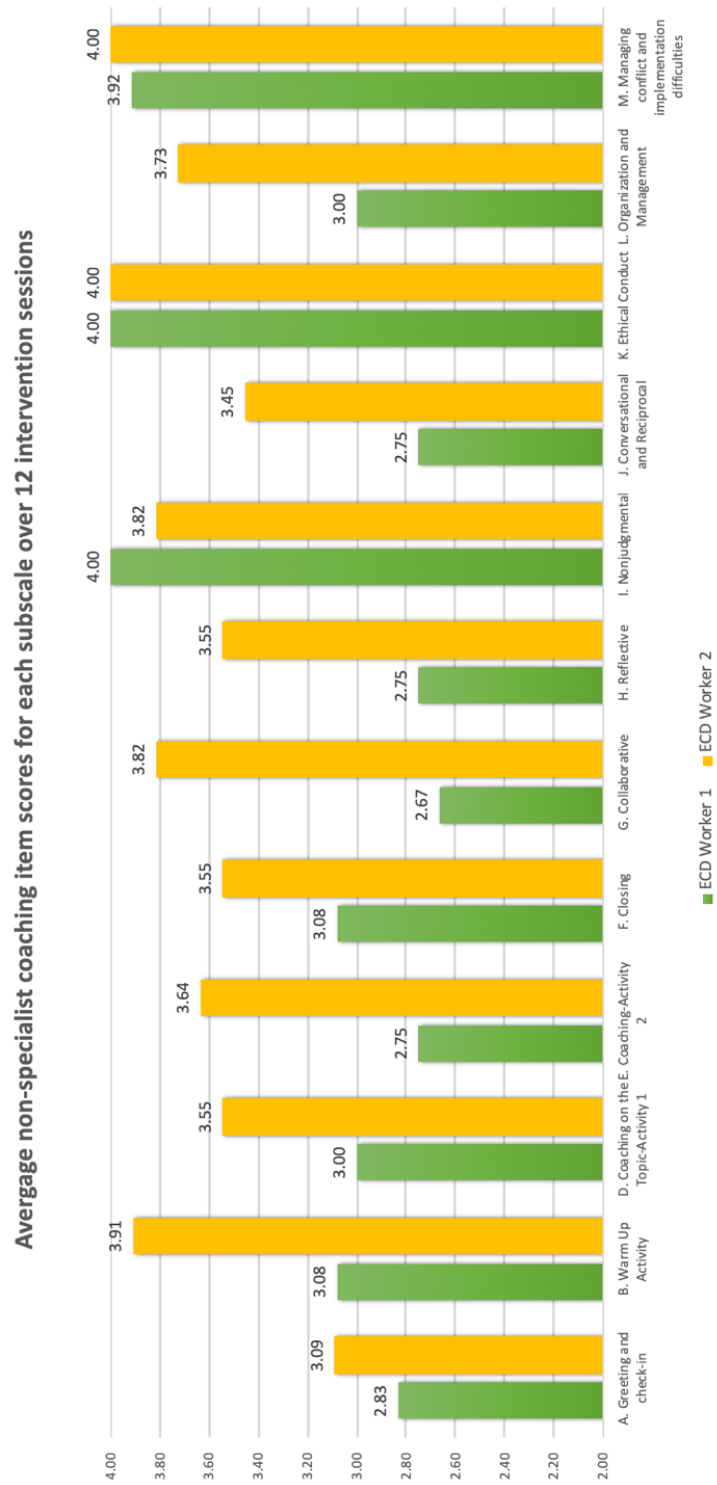


Table 3.3.5 includes the same average coaching fidelity rating items for ECD workers as Figure 3.3.4, but with items arranged from lowest to highest score along with the combined average coaching item score across 12 intervention sessions. ECD Worker 1 had an average item score of 3.15 out of 4 across 12 sessions (SD=0.20), and ECD Worker 2 had an average item score of 3.67 out of 4 (SD=0.20), and the total average for both caregivers across all twelve sessions are 3.41 out of 4. The five lowest ECD average coaching item scores were ‘greetings and check-in’; ‘conversational and reciprocal’, ‘reflective’, ‘coaching activity 2’ and ‘collaborative’. The three highest scoring items were related to the coaching characteristics of being non-judgmental, showing ethical conduct, and managing conflict and implementation difficulties.

Participant	ECD Worker 1	ECD Worker 2	Average Fidelity Score (Lowest to highest)
Greeting and check-in	2.83	3.09	2.96
Conversational and Reciprocal	2.75	3.45	3.10
Reflective	2.75	3.55	3.15
Coaching-Activity 2	2.75	3.64	3.19
Collaborative	2.67	3.82	3.24
Coaching on the Topic-Activity 1	3.00	3.55	3.27
Closing	3.08	3.55	3.31
Organization and Management	3.00	3.73	3.36
Warm Up Activity	3.08	3.91	3.50
Nonjudgmental	4.00	3.82	3.91
Managing conflict and implementation difficulties	3.92	4.00	3.96
Ethical Conduct	4.00	4.00	4.00
	3.15	3.67	3.41

Average fidelity score for all rating items			
--	--	--	--

Table: 3.3. 5: Individual and average scores on coaching fidelity rating items

Figure 3.3.5 illustrates ECD worker acquisition of coaching techniques (mean score of all Caregiver Fidelity items) over 12 intervention sessions. The x-axis of this graph shows time points for the 12 intervention sessions. Fidelity data from ECD Worker 1 and ECD Worker 2 are represented using blue and orange lines, respectively, on the graph. The y-axis of the graph presents the fidelity percentage, ranging from 0-100%. The graph hides part of y-axis (0-50%) where no ratings fell to visually better present the line fluctuation. Each percentage value is calculated by dividing the raw data by four and multiplying by 100. For example, if the raw data was 3, then calculation is conducted: $\frac{3}{4} \times 100\% = 75\%$, so 3 would be marked as 75% on this graph. The dashed line is presented on the graph to mark the 80% fidelity cutoff in order to give clear visualization of whether the coaching performance approached fidelity in each of the 12 sessions. The graph shows that ECD Worker 1 came close to fidelity (above 70% but lower than 80%) in sessions 9, 11 and reached fidelity in session 1, 2, 3, 4, 5 and 10. ECD Worker 2 surpassed 80% fidelity in all 11 of its recorded sessions.

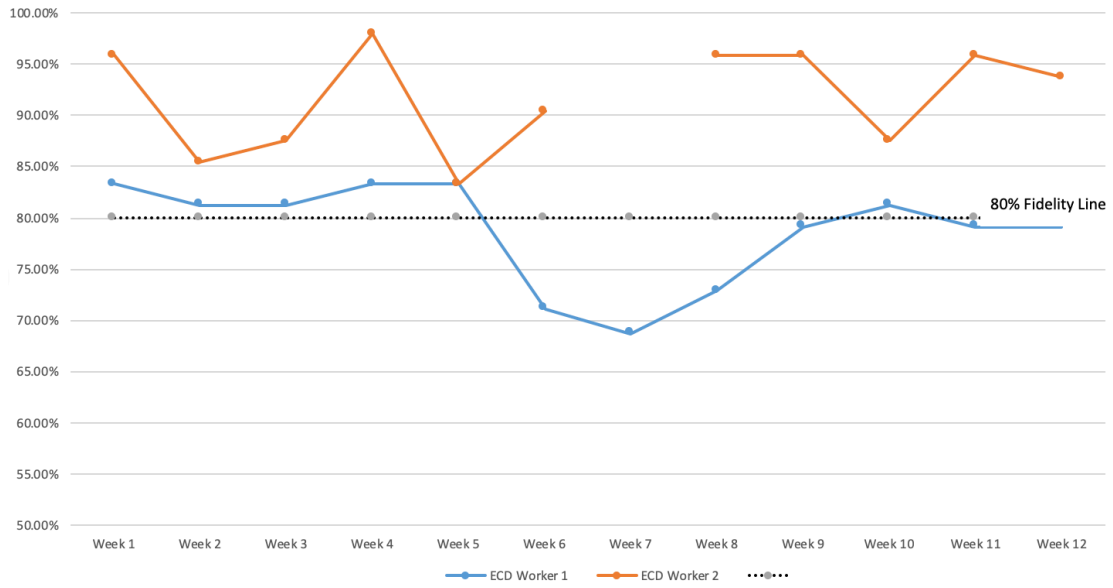


Figure 3.3.5 ECD Worker Average Coaching Fidelity Score per Session Across 12 Weeks

4. Discussion

ASDs account for substantial burden of disease across the lifespan and impose significant emotional and economic burden on ASD children and their families. Evidence-based interventions for ASD exist but are rarely available in LMICs due to scarce professional resources. ASD interventions led by non-specialists and caregivers can help fill the gap in ASD treatment services in LMICs. The purpose of this pre-pilot study was to assess the feasibility of an adapted ASD early intervention where caregivers are coached by non-specialist ECD workers in South Africa. The study documented the adaptation of the intervention and examined fidelity of intervention delivery for both the caregivers and the non-specialist coaches (ECD workers).

An intervention adaptation process is essential to adapt an intervention to a new cultural context and ensure that ASD interventions are acceptable and feasible. Importantly, adaptation must maintain the key components of an evidence-based intervention. In this pre-pilot study, results showed that some fidelity was achieved in the pre-pilot, but fidelity was not consistently observed. Difficulty with individual fidelity items can help the study team understand how to tailor the training and supervision approach to ensure competency on individual items, as discussed below.

Notably, neither caregiver consistently used a clear “Antecedents, Behavior, Consequences” (ABC) format during caregiver-child interactions. That is, the sequence of the caregiver’s natural reinforcement did not occur at a high level of implementation fidelity. The ABC is important, because it is used to teach young children new behaviors. It is possible that the caregivers were not able to translate the theoretical underpinning of

the ABC format to practical application. For example, to score well on “ABC format”, at first the caregivers needed to understand what is ABC, what behavioral teaching involves, and how these concepts are related to the ASD intervention that they are delivering. They must be able to understand antecedent, behaviors and consequences in each individual ASD child’s unique cases, and to be able to intervene to interrupt behavioral patterns.

A low average item fidelity score in Joint Activity Structure and Elaboration suggests that the caregivers did not consistently execute the four-part joint activity described in Table 2.5.2. Difficulties implementing the four-part joint activity appeared to be particularly relevant for Caregiver 1. The four-part joint activity structure is important because it provides the caregiver with a framework to engage with their child and teach their child new skills. Similarly, the caregivers need more enhancement on understanding what “prompting”, “fading”, and “chaining” mean, not only their literal meanings but to understand how to these techniques fit into their own child’s teaching sequences. As for low scores on the four-part joint activity and dyadic engagement, more practical training needs to be enforced to improve caregiver’s familiarity on performing the designed activities in a coordinated fashion. Sometimes the caregivers themselves might not consistently notice certain type of techniques, so such enforcement of practice would also require the contribution from the coach’s side as well.

Quality of dyadic engagement was the 3rd lowest average item score, and appeared particularly challenging for Caregiver 1. Quality of dyadic engagement is an important item on the Caregiver Fidelity Scale because it suggests that the caregiver is

implementing intervention skills to facilitate reciprocity and social engagement, which are key intervention targets in young children with ASD.

The fourth lowest average fidelity item score was “instructional techniques”. This suggests that the caregiver may be giving out poor quality teaching. The teaching process shows several marked problems in prompting, fading, chaining and managing errors. The fifth lowest average fidelity item score was “appropriateness of parent language for child's language level”. This suggests that the caregivers had some difficulty using language that was appropriate for expanding their child’s expressive language level. Caregiver attempts to label and narrate what their child is playing with, touching or using, while being positioned face to face with their child is a key ESDM intervention skill that was not consistently demonstrated.

In terms of ECD worker performance on coaching ESDM techniques, the fundamental coaching characteristics of being non-judgmental, managing conflict, and ethical conduct all reached close to full scores. This demonstrate that ECD Workers had the fundamental interpersonal skills to work with caregiver-child dyads. However, several criteria fell short in the ratings: the coaching characteristics of greetings and check-in; conversational and reciprocity with the caregiver; being reflective; and being collaborative with the caregiver during coaching sessions.

The lowest average item score was for ‘greeting and check-in’. Both ECD workers appeared to have difficulty with this item. This suggests that the ECD workers consistently disregarded one or more important element that should occur during this initial contact with the caregiver. These elements include reviewing any data the

caregiver brings into the session, actively listening to the caregiver without taking the lead, acknowledging the caregiver's effort, transitioning smoothly into caregiver-child interactions and finding a way to organize the caregiver's comments into the session's activities.

The second lowest average rating was for the caregiver coaching characteristic of 'conversational and reciprocal'. Notably, ECD worker 1 has significantly more difficulty with this coaching characteristic than ECD worker 2. Difficulty with this item suggests that the interaction between the ECD worker and caregiver was not consistently balanced, with either the ECD worker or the caregiver dominating the exchanges. Low reflective rating suggests that the coach did not fully reflect on the aspects including what the coach observed, the relationship between the learning goals and observed actions, effects of parent behavior on child behavior and emotional expressions that occurs during the coaching session. Low collaborative rating suggests the coaches fell short in joining the caregiver in common goals and acknowledging the parent's knowledge and expertise. Instead, the coach is may have sometimes taken an authoritative role rather than a collaborative one.

Lastly, low rating scores on coaching activity suggest the coach did not consistently use skills sufficiently to support parent attention and success at using the topic skill. The coach did not always adjust techniques according to caregiver's learning styles, understanding level, child goals and increasing success. The coaching occurred but the coach did not always provide enough support for parents since they only partially perform target skills during the activity.

Overall, the fidelity results suggest that coaches may require additional training and practice to reflect more actively on both the caregiver's verbal expression and non-verbal performances from the beginning to the closure of one session.

4.1 Future Implications

As the previous results presented, in this study, few caregiver intervention sessions reached the pre-identified goals for fidelity: only one session out of twelve for caregiver 1 and five sessions out of twelve for caregiver 2 passed the 80% cutoff line (6/24=25%). In addition, the fidelity scores were relatively unstable ($SD_{\text{Caregiver1}}=0.6$; $SD_{\text{Caregiver2}}=0.51$) across the 12 weeks of intervention. The results pointed to the need to tailor the training focus for coaching difficult techniques and providing materials to caregivers, as well as additional cultural tailoring to focus on hard-to-teach skills within this context.

These concepts are generally hard to master based on caregiver and coach performance in the pre-pilot study, and therefore may require further time and attention. ECD workers should also reinforce the importance of perseverance and possibly use motivational strategies during the coaching sessions to encourage caregivers as they are learning the core components of ESDM techniques. This can also be considered as a form of potential adaptation by adding emphases to the original coaching materials to make it more fit to different local environment.

There is limited literature on making cultural adaptation to interventions involving non-specialists in South Africa. South Africa is an extremely diverse country with

multiple ethnic groups and eleven official languages, not including those of immigrants and refugees (SSA, 2011). As a result, there are many factors to consider in adapting the intervention to reach more families in across the variety of South African contexts. In order to meet the goal of increasing the fidelity of the intervention, while maintaining the balance between intervention adaptation and fidelity, it is crucial to explore more systematic and structured guidelines to tailor the intervention to urban and rural areas, different languages and cultures, and challenges related to socioeconomic status.

Additional contextual adaptation to the original program may be needed to respond the barriers of early ASD interventions when other health challenges, such as crossovers with the South African HIV epidemics, are present in the same household. In addition, adaptations are needed to account for challenging socio-economic situations in families. Such adaptations may include financial budgeting and economic empowerment, time management, and addressing co-morbidities of other mental and physical diseases.

4.2 Limitations

The purpose of this pre-pilot study was to assess the feasibility of delivering a non-specialist caregiver coaching intervention, and to inform future iterations of the intervention. The results of the study must be interpreted in the context of its purpose, as well as its limitations.

The measures of fidelity may have been subject to measurement bias. Fidelity ratings were done by two experienced raters (a trainer in the intervention and a certified therapist in the intervention) who then discussed and reached consensus. The rating

evaluation may include some subjectivity, and it is quite possible that the two raters had different scoring tendencies. For example, when the caregiver performance is perceived as falling between score 3 and score 4, some researchers tend to give 3 and some tend to give 4. If this study is using a scale where the full score is 4 out of 4, then this one score difference can cause a 25% deviation in score results. Even if two raters discuss scoring and reach consensus, raters who are familiar to each other may also give out biased rating even when they reached agreement. Although ratings were done in a single setting, ratings of the intervention sessions may have varied across the 12 sessions, as the knowledge of the treatment and the rating scale is becoming more familiar and acquainted to the rater (Schoenwald et al., 2011). For future application of these rating scales, there should be organized protocols established to guarantee inter-rated agreement, and to handle any outliers, to maximize the reduction of potential subjectivity and to achieve higher consistency and objectivity of ratings.

This study is also limited by its small sample size. Due to the fact that there were only two dyads of caregiver-child and two ECD workers, it was not appropriate to perform any statistical tests with the current sample. Future research would benefit from a larger sample, which would allow researchers to examine the correlation between caregiver fidelity scores and coaching fidelity scores, to test a hypothesis that better fidelity to coaching produces better fidelity in caregiver performance.

With only two caregiver-child dyads, it is difficult to generalize the feasibility of the intervention. However, these data provided valuable information for future adaptation of training procedures and the intervention model. Additionally, the participant

recruitment process was limited to the Western Cape Province of South Africa, which is experiencing high growth, lower unemployment rates, and less income inequality (as per the Gini coefficient) than the national averages (Stats SA, 2012). Thus, any measures of feasibility cannot be assumed to extend to other geographic locations. Finally, the study is limited by missing data, as one session for caregiver 2 was missing due to the malfunction of video recording equipment. Since there are only twelve weeks of data, losing one out of twelve sessions means losing almost ten percent of all data; thus, guaranteeing intervention sessions are all recorded is crucial and indispensable.

5. Conclusion

Due to the lack of mental health specialists in lower-resourced areas, it is extremely challenging for ASD children to receive long-term ASD intervention (WHO, 2015b). Involving non-specialists who can coach caregivers on how to act as daily ASD therapists of their children may help to expand the reach of early ASD intervention. This pre-pilot study identified opportunities to target on-going supervision of non-specialist coaches to support effective coaching skills throughout the intervention program. Additional pilot research on this model, followed by a randomized controlled trial, has the potential to contribute to the global ASD field by examining the effectiveness of a locally adapted version of an evidence-based early ASD. If successful, this model can have a sustained impact on the delivery of services for ASD and potentially other mental disorders in diverse low-resourced communities, and can alleviate pressure on public health systems.

6. Appendix

Coaching Fidelity Scale

Item	What does a score 4 out of 4 session looks like
A. Greeting and check-in	The parent(s) share progress and challenges since the past session. The therapist shows interests, listens actively, follows up as needed, and acknowledges their efforts over the week and on the data sheets that are collected. This opening transitions smoothly into parent-child activity.
B. Warm Up Activity	The warm up activity occurs in response to the previous session's theme. All 5 parts are present. The coach allows the activity to occur without interruption, or with only the most minor comments that do not interrupt the play. The parent(s) provides some evaluation of the activity at the coach's invitation; the coach provides constructive comments concerning parent(s) behavior and child response afterward and there is a smooth transition to the next activity.
C. Introduction of the Topic	The topic is clearly identified and a plan for the session is laid out. These are tied into parent goals for the child, and into previous observations or discussions with the parent(s). Parent buy-in is sought and gained. The presentation uses multimodal features and adequate talking time well fitted to this family's learning style and needs. Assess understanding with open-ended questions. Parent values and priorities are addressed.
D. Coaching on the Topic-Activity 1	Coaching occurs and is successful at supporting parent use of target skill and elicitation of child skill. Coach adjusts techniques according to parent(s)' learning styles, understanding level, child goals, and increasing success. Strategies tie parent(s) actions to child behavior and goals with practice across at least two activities. Parent(s) has used reflection and evaluation to build skills. Parent(s) can tie practice to child goals across different activities or settings at home.
E. Coaching-Activity-2	
F. Closing	The closing addresses topics still open, generalization across daily activities, and ends the session smoothly. Conversation has been balanced, reflection and evaluation have occurred, details of next session addressed, clear goodbyes to all, and

	smooth transition out the door.
G. Collaborative	The coach collaborates with the parent(s) to establish and reach common goals. Each shares expertise with the other, and conveys recognition and respect for the other's knowledge and abilities. The coach asks questions, listens, and summarizes parent(s) responses to identify goals, topics, and concerns. Parent(s) also asks questions, listen, and reflect. The collaboration seems well-worked out and comfortable for all.
H. Reflective	The coach reflects on most of the five areas, provides transparent lines of thought from reflection to action, and supports the parent(s)' reflections and evaluative processes. There are enough relevant examples elicited from the session and from opportunities at home to enhance the parent(s)' knowledge and practice on the targeted topics before the next session. Reflection/evaluation leads to action plans.
I. Nonjudgmental	The coach's feedback across the session is predominantly descriptive rather than evaluative and it consistently highlights relations between parent actions and child behavior ("I noticed that when you did X your child typically responded with Y," "It seemed like whenever X happened, Y followed"); with enough examples to support parent understanding and practice before the next session.
J. Conversational and Reciprocal	The coach interacts with the parent(s) as a partner, sensitive to the timing of conversation, staying on-topic, and sharing control. The coach does not interrupt the parent(s) unless it is with permission and in the service of the communicative exchange, e.g. re-righting digression, asking for clarification, answering a question that was asked but lost, restatement to check understanding, etc. Turns are balanced, and partners command a fairly equal amount of "floor time".
K. Ethical Conduct	The coach maintains appropriate professional behavior and ethical conduct throughout the session. Any self-disclosure serves the purpose of supporting parent learning or parent experience.
L. Organization and Management	The session is well organized, both temporally and physically. The session's activities flow according to the plan, or, if plan is derailed by child need, a new organization is developed and essential parts are not lost. The session ends on time, the room

	is well set up for the child and family, and materials and activities are managed so that the child and family are well organized by the therapist's management of the setting and session.
M. Managing conflicting and implementation difficulties	There is no conflict in the session. Or, in an exchange in which there is a conflict between therapist and parent(s), the following interactions the therapist demonstrates awareness of underlying issues, invites parent(s) to share viewpoint and listens and acknowledges their views, finds a point of convergence that results in a resolution of the conflict and a new solution that all can embrace, and this process strengthens the parent-coach alliance and refocuses all on child intervention needs.

Caregiver Fidelity Scale

Code Definitions

The scores used in the fidelity system carry the following meaning when applied to video coding of an individual joint activity routine:

5	A score of 5 represents the best possible example of this teaching technique or skill. This sample represents optimal examples of the teaching skill, and the coder does not see anything that the parent could have done to improve on this behavior. This is expert level performance.
4	A score of 4 represents a competent but not optimal example of this teaching technique. The skill might have been performed in a more refined or expert way by a master ESDM therapist, but there are no mistakes in the execution of this skill and it represents a completely acceptable display of this skill. This is a fully competent level.
3	A score of 3 represents a parent behavior that is performed with strengths, but also some weaknesses. Overall there are more strengths than weaknesses, but there are evident oversights or mistakes according to the specified criteria. A person at this level in most of his or her teaching needs more refinement of his or her skills before they are using ESDM competently. The individual will continue to work with children, but requires additional supervision and feedback to improve competency in these areas. This is a mixed level of competence.

2	A score of 2 represents a flawed display of this teaching behavior. There is some effort to use the specified teaching practice but there are more weaknesses than strengths in this example. This is not an acceptable level of performance and a person at this level needs more training and supervision in this technique before working alone with children.
1	A score of 1 represents an absent or a poor example of the specified practice. A person at this level needs full training in the model before working alone with children.

Item	5 out of 5 Performance Code Definition
A. Management of child attention	Parent has child attention at the beginning of the episode and maximizes and sustains it through a well-developed teaching activity and needed adjustments through multiple practice opportunities. The child shows coordinated or alternating attention to parent and teaching activity. Demonstrates optimal management of attention.
B. ABC format	Many teaching exchanges occur during the activity – on the average they occur every 10-20 seconds. The A, B, and C segments are quite clear, and it is obvious what child behavior the parent is trying to elicit and what behaviors are being reinforced. The number of repetitions is well matched to the child’s learning needs. This is optimal teaching.
C. Instructional techniques	. This segment contains optimal examples of the principles above. The parent skillfully uses fading, shaping, prompting, and chaining techniques to increase the child’s independent performance of the learning objectives during the learning activity.
D. Modulating child affect/arousal	Child does not display any problems with arousal or affect during this episode. Or, the child shows some affect/arousal problems and the parent shows great skill in finding ways to optimize the child’s state quickly resulting in a very successful learning activity with many learning opportunities and an engaged child.
E. Management of unwanted behavior	No unwanted behaviors as defined above occurred during this episode, or, they occur but parent management did not contribute to the unwanted behaviors. The parent manages the

	behavior skillfully and uses positive techniques that successfully redirect child, elicit a more appropriate behavior, and re-establish child engagement and positive affect for learning as soon as possible. This represents optimal management of the situation.
F. Quality of dyadic engagement	Turn taking and dyadic engagement occurs throughout the episode. The child is actively involved in parent turns, including giving toys, co-constructing, helping, or cuing the parent's turn. Reciprocity and social engagement permeate the teaching activity and this is an optimal example of incorporating reciprocal dyadic engagement into teaching.
G. Parent optimizes child motivation	The episode demonstrates a highly motivated child who chooses the activity and is very interested in the activity. The child engages repeatedly in the learning activities that are presented, responds consistently to parent instruction, and initiates repeated communicative behaviors requesting the learning activities. The parent demonstrates optimal use of the four variables above. The parent is adept at making small adjustments and creating many child choices to maintain high motivation throughout the activity.
H. Parent use of positive affect	The parent displays rich, genuine and natural positive affect throughout the episode matched by child positive affect. Positive affect permeates the episode, is well matched to child needs and capacities, does not over arouse the child, and serves teaching well.
I. Parent sensitivity and responsivity	The parent demonstrates optimal sensitivity and responsivity to child cues. The parent is maximally attuned to the child's communications, both directed and undirected. The parent reads the child very well or makes every effort to interpret the child's meaning. The parent uses a full range of responses: restatement, modeling, expansion, affirmation through repetition.
J. Multiple varied communicative opportunities	This is an optimal example of the parent scaffolding multiple communications involving several different communicative functions throughout the episode as specified in the child's objectives, including opportunities to request, protest, comment, ask for help, greet, name, expand, and so on. The range of pragmatic and communicative opportunities fit well with the child's language level. For an object-oriented activity, there are multiple child communications per minute. For a sensory social

	<p>routine, child communication (including gaze and smiles) occurs approximately every 10 seconds. The parent uses a range of techniques including modeling, restatement, expansion of child utterances, and repetition of child utterances embedded in meaningful activities. No clear opportunities for child communication were missed, and child's communication objectives are woven throughout the activity.</p>
<p>K. Parent's language for child's level</p>	<p>Parent language is consistently appropriate developmentally and pragmatically for the child's verbal and nonverbal communicative intent and capacity. Parent generally follows the one-up rule, responds to child's communications with appropriate language, narrates child and parent acts or themes appropriately, and uses language to demonstrate a variety of pragmatic functions, semantic relations, and syntactic combinations.</p>
<p>L. Joint activity and elaboration</p>	<p>Parent provides an optimal four part joint activity including a well-developed closure. Parent demonstrates optimal and imaginative elaboration of this activity, targeting many objectives. Parent supports the child's learning by combining skills from objectives in different domains in flexible teaching. (Note: If the child needs many repetitions to master this skill and the child is highly motivated, then do not score down due to lack of theme and variation. However, there should always be more than one child objective targeted in an activity.)</p>
<p>M. Transition between activities</p>	<p>Transition is optimally managed. Parent scaffolds child's shift of interest by closing down one activity at the appropriate time and bringing up another, so that the child's learning in both activities is maximized and interest flows from one activity to the next with minimal down time. Child chooses and initiates the next activity.</p>

7. References

- Aarons, G. A. (2004). Mental health provider attitudes toward adoption of evidence-based practice: the Evidence-Based Practice Attitude Scale (EBPAS). *Mental Health Services Research, 6*(2), 61–74.
- Aarons, G. A., Green, A. E., Palinkas, L. A., Self-Brown, S., Whitaker, D. J., Lutzker, J. R., ... Chaffin, M. J. (2012). Dynamic adaptation process to implement an evidence-based child maltreatment intervention. *Implementation Science, 7*(1). <https://doi.org/10.1186/1748-5908-7-32>
- Abubakar, A., Ssewanyana, D., & Newton, C. R. (2016). A Systematic Review of Research on Autism Spectrum Disorders in Sub-Saharan Africa. *Behavioural Neurology, 2016*, 1–14. <https://doi.org/10.1155/2016/3501910>
- Akshoomoff, N., Corsello, C., & Schmidt, H. (2006). The Role of the Autism Diagnostic Observation Schedule in the Assessment of Autism Spectrum Disorders in School and Community Settings. *The California School Psychologist: CASP, 11*, 7–19.
- Alhazmi, A., Petersen, R., & Donald, K. A. (2018). Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatrica, 1–6*. <https://doi.org/10.1017/neu.2018.5>
- Autism Speaks Autism Treatment Network, 2012
- Backer, T. E. (2001). *Finding the Balance—Program Fidelity and Adaptation in Substance Abuse Prevention: A State-of-the Art Review*. Center for Substance Abuse Prevention, Rockville, MD.
- Baranek, G. T., Watson, L. R., Turner-Brown, L., Field, S. H., Crais, E. R., Wakeford, L., ... Reznick, J. S. (2015). Preliminary Efficacy of Adapted Responsive Teaching for Infants at Risk of Autism Spectrum Disorder in a Community Sample. *Autism Research and Treatment, 2015*, 1–16. <https://doi.org/10.1155/2015/386951>
- Bello-Mojeed, M. A., & Bakare, M. O. (2013). Improving Treatment of Children with Autism Spectrum Disorder in Low- and Middle-Income Countries: The Role of Non-specialist Care Providers. *PLoS Medicine, 10*(12), e1001573. <https://doi.org/10.1371/journal.pmed.1001573>

- Benatar, S. R. (2013). The challenges of health disparities in South Africa. *South African Medical Journal*, 103(3), 154. <https://doi.org/10.7196/SAMJ.6622>
- Brownson, R. C., Colditz, G. A., & Proctor, E. K. (2012). *Dissemination and Implementation Research in Health Translating Science to Practice*. Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780199751877.001.0001>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bloomfield, S. (2016). *Subscale C: Eye and Hand Coordination*. PowerPoint Presentation on the developments in the *Griffiths III* on the ARICD site.
- Carr, T., & Lord, C. (2016). A pilot study promoting participation of families with limited resources in early autism intervention. *Research in Autism Spectrum Disorders*, 25, 87–96. <https://doi.org/10.1016/j.rasd.2016.02.003>
- Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science*, 2(1). <https://doi.org/10.1186/1748-5908-2-40>
- Carter, A. S., Messinger, D. S., Stone, W. L., Celimli, S., Nahmias, A. S., & Yoder, P. (2011). A randomized controlled trial of Hanen's 'More Than Words' in toddlers with early autism symptoms: Hanen's 'More Than Words' RCT. *Journal of Child Psychology and Psychiatry*, 52(7), 741–752. <https://doi.org/10.1111/j.1469-7610.2011.02395.x>
- Carvalho, M. L., Honeycutt, S., Escoffery, C., Glanz, K., Sabbs, D., & Kegler, M. C. (2013). Balancing Fidelity and Adaptation: Implementing Evidence-Based Chronic Disease Prevention Programs. *Journal of Public Health Management and Practice*, 19(4), 348–356. <https://doi.org/10.1097/PHH.0b013e31826d80eb>
- Castro, F. G., Barrera, M., & Martinez, C. R. (2004). The cultural adaptation of prevention interventions: resolving tensions between fidelity and fit. *Prevention Science: The Official Journal of the Society for Prevention Research*, 5(1), 41–45.
- Cape Town Population. (2018-02-09). Retrieved 2018-07-24, from <http://worldpopulationreview.com/>

Census 2011, Census in brief, Retrieved from:

http://www.statssa.gov.za/census/census_2011/census_products/Census_2011_Census_in_brief.pdf

Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., ... Centers for Disease Control and Prevention (CDC). (2016). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.: 2002)*, 65(3), 1–23. <https://doi.org/10.15585/mmwr.ss6503a1>

Cidav, Z., Munson, J., Estes, A., Dawson, G., Rogers, S., & Mandell, D. (2017). Cost Offset Associated With Early Start Denver Model for Children With Autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(9), 777–783. <https://doi.org/10.1016/j.jaac.2017.06.007>

Cohen, D. J., Crabtree, B. F., Etz, R. S., Balasubramanian, B. A., Donahue, K. E., Leviton, L. C., ... Green, L. W. (2008). Fidelity versus flexibility: translating evidence-based research into practice. *American Journal of Preventive Medicine*, 35(5 Suppl), S381–389. <https://doi.org/10.1016/j.amepre.2008.08.005>

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, 374(9692), 817–834. [https://doi.org/10.1016/S0140-6736\(09\)60951-X](https://doi.org/10.1016/S0140-6736(09)60951-X)

Curran, G. M., Bauer, M., Mittman, B., Pyne, J. M., & Stetler, C. (2012). Effectiveness-implementation Hybrid Designs: Combining Elements of Clinical Effectiveness and Implementation Research to Enhance Public Health Impact. *Medical Care*, 50(3), 217–226. <https://doi.org/10.1097/MLR.0b013e3182408812>

Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science*, 4(1). <https://doi.org/10.1186/1748-5908-4-50>

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., ... Varley, J. (2010). Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model. *PEDIATRICS*, 125(1), e17–e23. <https://doi.org/10.1542/peds.2009-0958>

- Dawson, Geraldine. (2016). Why It's Important to Continue Universal Autism Screening While Research Fully Examines Its Impact. *JAMA Pediatrics*, 170(6), 527–528. <https://doi.org/10.1001/jamapediatrics.2016.0163>
- de Vries, P. J. (2016). Thinking globally to meet local needs: autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, 29(2), 130–136. <https://doi.org/10.1097/WCO.0000000000000297>
- Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., & Dawson, G. (2015). Long-Term Outcomes of Early Intervention in 6-Year-Old Children With Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(7), 580–587. <https://doi.org/10.1016/j.jaac.2015.04.005>
- Flynn, J. R. (2009). *What is intelligence: Beyond the Flynn Effect* (expanded paperback ed. Cambridge University Press: (The term was originally coined by Herrnstein and Murray).
- Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N., & de Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: stakeholder perspectives from the Western Cape province. *Journal of Child & Adolescent Mental Health*, 30(3), 149–165. <https://doi.org/10.2989/17280583.2018.1525386>
- Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-saharan africa: A comprehensive scoping review: Autism spectrum disorder in sub-Saharan Africa. *Autism Research*, 10(5), 723–749. <https://doi.org/10.1002/aur.1766>
- Forssberg, H., (1998) *The Neurophysiology of Manual Skill Development in The Psychobiology of the Hand* Ed. Connelly, K.J., Clinics in Developmental medicine No. 147 pp 100-105 Mac Keith Press
- GBD 2015 Disease and Injury Incidence and Prevalence Collaborators. (2016). Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet (London, England)*, 388(10053), 1545–1602. [https://doi.org/10.1016/S0140-6736\(16\)31678-6](https://doi.org/10.1016/S0140-6736(16)31678-6)
- Green, E. (2016). *Subscale E: Gross Motor*. PowerPoint Presentation on the developments in the *Griffiths III* on the ARICD site.

- Green, J., Charman, T., Pickles, A., Wan, M. W., Elsabbagh, M., Slonims, V., ... Johnson, M. H. (2015). Parent-mediated intervention versus no intervention for infants at high risk of autism: a parallel, single-blind, randomised trial. *The Lancet Psychiatry*, 2(2), 133–140. [https://doi.org/10.1016/S2215-0366\(14\)00091-1](https://doi.org/10.1016/S2215-0366(14)00091-1)
- Griffiths, R. (1935). *Imagination in early childhood*. London: Routledge.
- Griffiths, R. (1954). *The abilities of babies, 0–2 years*. London: University of London Press.
- Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. (2017). The importance of context in early autism intervention: A qualitative South African study. *Autism: The International Journal of Research and Practice*, 1362361317716604. <https://doi.org/10.1177/1362361317716604>
- Hutton, N. K., Mitchell, C., & van der Riet, M. (2016). Assessing an isiZulu questionnaire with educators in primary schools in Pietermaritzburg to establish a baseline of knowledge of Autism Spectrum Disorder. *BMC Pediatrics*, 16(1). <https://doi.org/10.1186/s12887-016-0721-8>
- Jack, H., Wagner, R. G., Petersen, I., Thom, R., Newton, C. R., Stein, A., ... Hofman, K. J. (2014). Closing the mental health treatment gap in South Africa: a review of costs and cost-effectiveness. *Global Health Action*, 7, 23431.
- Kasari, C., Gulsrud, A. C., Wong, C., Kwon, S., & Locke, J. (2010). Randomized Controlled Caregiver Mediated Joint Engagement Intervention for Toddlers with Autism. *Journal of Autism and Developmental Disorders*, 40(9), 1045–1056. <https://doi.org/10.1007/s10803-010-0955-5>
- Koegel, R. J. L., Camarate, S., Koegel, L. K., Bea-Tall, A., & Smith, A. E. (1998) Increasing speech intelligibility in children with autism. *Journal of Autism and Developmental Disorders*, 28(3), 241-251.
- Lane, H. (2016). *Subscale D: Personal, Social, Emotional*. PowerPoint Presentation on the developments in the *Griffiths III* on the ARICD site.
- Lazaratou, H., Economou, M., & Dikeos, D. (2017). The necessity of early intervention in autism. *The Journal of Pediatrics*, 184, 240–241. <https://doi.org/10.1016/j.jpeds.2016.12.030>

- Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Autism diagnostic observation schedule: A standardized observation of communicative and social behavior. *Journal of Autism and Developmental Disorders*, 19(2), 185–212. <https://doi.org/10.1007/BF02211841>
- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., Bishop, S. L., & Schedule, A. A. D. O. (2015). ADOS-2. *Manual (Part I): Modules*, 1-4.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., ... & Rutter, M. (2000). The Autism Diagnostic Observation Schedule—Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of autism and developmental disorders*, 30(3), 205-223.
- Lyall, K., Croen, L., Daniels, J., Fallin, M. D., Ladd-Acosta, C., Lee, B. K., ... & Newschaffer, C. (2017). The Changing Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health*, 38, 81–102. <https://doi.org/10.1146/annurev-publhealth-031816-044318>
- Marsiglia, F. F., & Booth, J. M. (2015). Cultural Adaptation of Interventions in Real Practice Settings. *Research on Social Work Practice*, 25(4), 423–432. <https://doi.org/10.1177/1049731514535989>
- Mayosi, B. M., & Benatar, S. R. (2014). Health and Health Care in South Africa — 20 Years after Mandela. *New England Journal of Medicine*, 371(14), 1344–1353. <https://doi.org/10.1056/NEJMs1405012>
- McConachie, H., & Robinson, G. (2006). What services do young children with autism spectrum disorder receive? *Child: Care, Health and Development*, 32(5), 553–557. <https://doi.org/10.1111/j.1365-2214.2006.00672.x>
- McGovern, C. W., & Sigman, M. (2005). Continuity and change from early childhood to adolescence in autism. *Journal of Child Psychology and Psychiatry*, 46(4), 401–408. <https://doi.org/10.1111/j.1469-7610.2004.00361.x>
- Mihalic, S. (2004). The importance of implementation fidelity. *Emotional and Behavioral Disorders in Youth*, 4(4), 83-105.
- Morrison, D. M., Hoppe, M. J., Gillmore, M. R., Kluver, C., Higa, D., & Wells, E. A. (2009). Replicating An Intervention: The Tension Between Fidelity and Adaptation. *AIDS Education and Prevention*, 21(2), 128–140. <https://doi.org/10.1521/aeap.2009.21.2.128>

- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health, 28*, 235–258. <https://doi.org/10.1146/annurev.publhealth.28.021406.144007>
- Newton, C. R., & Chugani, D. C. (2013). The continuing role of ICNA in Africa: how to tackle autism? *Developmental Medicine & Child Neurology, 55*(6), 488–489. <https://doi.org/10.1111/dmcn.12150>
- Paradice, R. (2016). *Scale B: Language and Communication*. PowerPoint Presentation on the developments in the *Griffiths III* on the ARICD site.
- Pérez, D., Van der Stuyft, P., Zabala, M. del C., Castro, M., & Lefèvre, P. (2015). A modified theoretical framework to assess implementation fidelity of adaptive public health interventions. *Implementation Science, 11*(1). <https://doi.org/10.1186/s13012-016-0457-8>
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-Specialist Psychosocial Interventions for Children and Adolescents with Intellectual Disability or Lower-Functioning Autism Spectrum Disorders: A Systematic Review. *PLoS Medicine, 10*(12), e1001572. <https://doi.org/10.1371/journal.pmed.1001572>
- Rogers, S. J., Estes, A., Vismara, L., Munson, J., Zierhut, C., Greenson, J., ... Talbott, M. (2019). Enhancing Low-Intensity Coaching in Parent Implemented Early Start Denver Model Intervention for Early Autism: A Randomized Comparison Treatment Trial. *Journal of Autism and Developmental Disorders, 49*(2), 632–646. <https://doi.org/10.1007/s10803-018-3740-5>
- Rogers SJ, Vismara, L., Dawson, G., & Stahmer, A. . Help Is in Your Hands: A Web-Based Tool to Help Parents Build Their Toddlers' Social and Communication Development. 2017. Accessed 10/4/18, 2018.
- Rogers, S. J., Vismara, L., Wagner, A. L., McCormick, C., Young, G., & Ozonoff, S. (2014). Autism treatment in the first year of life: a pilot study of infant start, a parent-implemented intervention for symptomatic infants. *Journal of Autism and Developmental Disorders, 44*(12), 2981–2995. <https://doi.org/10.1007/s10803-014-2202-y>
- Rogers, Sally J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., ... Dawson, G. (2012). Effects of a Brief Early Start Denver Model (ESDM)–Based Parent Intervention on Toddlers at Risk for Autism Spectrum Disorders: A Randomized

Controlled Trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(10), 1052–1065. <https://doi.org/10.1016/j.jaac.2012.08.003>

Sarosha Pillay, Duncan, M., & Vries, P. J. D. (2017). How many children with Autism Spectrum Disorder are there in South African Schools: A systematic database search for known cases of ASD in the Western Cape. *Unpublished*.
<https://doi.org/10.13140/rg.2.2.15109.45281>

Schertz, H. H., Odom, S. L., Baggett, K. M., & Sideris, J. H. (2013). Effects of Joint Attention Mediated Learning for toddlers with autism spectrum disorders: An initial randomized controlled study. *Early Childhood Research Quarterly*, 28(2), 249–258.
<https://doi.org/10.1016/j.ecresq.2012.06.006>

Schoenwald, S. K., Garland, A. F., Chapman, J. E., Frazier, S. L., Sheidow, A. J., & Southam-Gerow, M. A. (2011). Toward the Effective and Efficient Measurement of Implementation Fidelity. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(1), 32–43. <https://doi.org/10.1007/s10488-010-0321-0>

Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., ... Halladay, A. (2015). Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45(8), 2411–2428. <https://doi.org/10.1007/s10803-015-2407-8>

South African National Treasury. 2010 Estimates of National Health Expenditure. Pretoria: South African National Treasury, 2010.

South African National Treasury. 2018 Estimates of National Health Expenditure. Pretoria: South African National Treasury, 2018.

Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. 2016. Vineland Adaptive Behavior Scales – 3rd Edition (Vineland-3). Access on 02/01/2019, 2019.

Stahmer, A. C., Rieth, S., Lee, E., Reisinger, E. M., Mandell, D. S., & Connell, J. E. (2015). TRAINING TEACHERS TO USE EVIDENCE-BASED PRACTICES FOR AUTISM: EXAMINING PROCEDURAL IMPLEMENTATION FIDELITY: Training Teachers in Autism Practices. *Psychology in the Schools*, 52(2), 181–195.
<https://doi.org/10.1002/pits.21815>

STATS SA (Statistics South Africa), 2018, Retrieved from:
<http://www.statssa.gov.za/?m=2018>

- Staples, K. L., MacDonald, M., & Zimmer, C. (2012). Assessment of Motor Behavior Among Children and Adolescents with Autism Spectrum Disorder. In *International Review of Research in Developmental Disabilities* (Vol. 42, pp. 179–214). Elsevier. <https://doi.org/10.1016/B978-0-12-394284-5.00007-3>
- Stirman, S. W., Miller, C. J., Toder, K., & Calloway, A. (2013). Development of a framework and coding system for modifications and adaptations of evidence-based interventions. *Implementation Science*, 8(1). <https://doi.org/10.1186/1748-5908-8-65>
- Stroud, L. (2016). *Scale A: Foundations of Learning*. PowerPoint Presentation on the developments in the *Griffiths III* on the ARICD site.
- van Ginneken, N., Tharyan, P., Lewin, S., Rao, G. N., Meera, S., Pian, J., ... Patel, V. (2013). Non-specialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle-income countries. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD009149.pub2>
- van Heijst, B. F., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, 19(2), 158–167. <https://doi.org/10.1177/1362361313517053>
- Vismara, L. A., Colombi, C., & Rogers, S. J. (2009). Can one hour per week of therapy lead to lasting changes in young children with autism? *Autism*, 13(1), 93–115. <https://doi.org/10.1177/1362361307098516>
- Vismara, L.A., & Bogin, J. (2009). Steps for implementation: Pivotal response training. Sacramento, CA: The National Professional Development Center on Autism Spectrum Disorders, The M.I.N.D. Institute, The University of California at Davis School of Medicine.
- Vismara, L. A., McCormick, C. E. B., Shields, R., & Hessel, D. (2018). Extending the Parent-Delivered Early Start Denver Model to Young Children with Fragile X Syndrome. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-018-3833-1>
- Waltz, J., Addis, M. E., Koerner, K., & Jacobson, N. S. (1993). Testing the integrity of a psychotherapy protocol: assessment of adherence and competence. *Journal of Consulting and Clinical Psychology*, 61(4), 620–630.
- Western Cape Economic Overview". Westgro. Archived from the original on 25 December 2010. Retrieved 14 May 2011.

Wechsler, D. (1958). *The measurement and appraisal of adult intelligence* (4th ed.). Baltimore, MD: Williams & Wilkins.

Wetherby, A. M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-Implemented Social Intervention for Toddlers With Autism: An RCT. *Pediatrics*, *134*(6), 1084–1093.
<https://doi.org/10.1542/peds.2014-0757>

WHO. (2015b). Global Health Observatory Data Repository. Retrieved from
<http://apps.who.int/gho/data/node.main.MHHR?lang=en>

Wong, V. C. N., & Kwan, Q. K. (2010). Randomized Controlled Trial for Early Intervention for Autism: A Pilot Study of the Autism 1-2-3 Project. *Journal of Autism and Developmental Disorders*, *40*(6), 677–688.
<https://doi.org/10.1007/s10803-009-0916-z>