An Examination of an Adaptive Parent-Mediated Intervention Delivered via Telehealth for Toddlers ‘At Risk’ of Autism Spectrum Disorder in the United Arab Emirates

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Rasha Alhejailan

Table of Contents

Summary

Best practice in interventions for children below the age of three years with suspected or confirmed autism diagnosis is to include behavioural and developmental approaches as early as possible, and ensure active involvement of parents (e.g., Zwaigenbaum et al., 2015). Naturalistic Developmental Behaviour Interventions (NDBIs) is an evidence-based approach that integrates the principles of both Applied Behaviour Analysis and developmental science (Schreibman et al., 2015). A crucial element in the success of early intervention, especially for toddlers, is parental involvement. Parent-mediated intervention is an approach whereby professionals support parents in fostering their child's learning and development, by embedding intervention strategies across natural everyday activities (Wetherby et al., 2018). Despite strong evidence supporting the importance of early intervention in increasing positive outcomes, there are major barriers to accessing services. Utilising a telehealth model in the delivery of parent-mediated intervention, can potentially narrow the service-need gap. Given the heterogeneity of Autism clinical presentation, and the diversity within families and cultures, recent recommendations support a novel adaptive, 'stepped care', approach in delivering intervention (Lord et al., 2021). In the United Arab Emirates, Autism research and service provisions are still at their infancy, and there continues to be a gap between policy and practice, despite recent efforts of policy makers. The aim of the current research programme was to explore the introduction of a contextually fit, adaptive parent-mediated NDBI delivered via telehealth to parents of toddlers 'at risk' of autism in the UAE.

In Chapter 1, an overview of the evidence base for early intervention in young children with Autism Spectrum Disorder is provided, including NDBIs, parent-mediated approaches, and the utilisation of telehealth. The barriers to accessing early intervention,

and the resulting service-need gap are illustrated, specifically within the context of the United Arab Emirates.

Chapter 2 describes early experiences from a pilot trial of a bilingual NDBI intervention program, conducted via telehealth during the COVID-19 pandemic, which informed the development of bilingual (Arabic and English) online learning modules based on the Early Start Denver Model, and the adaptation and translation of outcome measures to evaluate the intervention.

Chapter 3 describes the outcomes from a pilot study conducted to examine the feasibility of individual and group-based coaching of parent mediated NDBI delivered via telehealth to parents of toddlers ‘at risk’ of Autism in the UAE. Outcomes support the initial feasibility and acceptability of the provided intervention, as well as a reported improvement in parent knowledge, and parent reported child outcomes. A discussion of the challenges and limitations of the study highlight the importance of an adaptive, ‘stepped care’, approach that takes into account the diversity and variability of parent needs and preferences.

Chapter 4 investigates the implementation of an adaptive parent-mediated NDBI delivered via telehealth, adopting a Sequential Multiple Assignment Randomised Trial design. Reported outcomes support the feasibility and acceptability of the adaptive intervention. Utilising a rapid measure of response to intervention halfway through the intervention program was shown to be useful in identifying ‘slow responders’ to intervention. Subsequently augmenting intervention for slow responders with parent-coaching was shown to lead to a more positive outcome, including improved parent knowledge; decreased burden of autism on family experience; parent reported improvement in social engagement, communication, and play; and improved parent response to intervention. In Chapter 5, qualitative data from post-intervention semi-structured interviews are collated and analysed, and emerging themes related to parents' opinions on the characteristics of the program, and their perceptions and attitudes towards intervention are described. Parents' perceptions of the strengths and limitations of the intervention, as well as identified facilitators and barriers in implementation are discussed.

Chapter 6 describes the process of developing and tailoring implementation strategies based on the barriers and facilitators identified in Chapter 5, utilising the EPIS framework. The implementations strategies are discussed within the context of the recent Lancet recommendations for 'stepped care' model for interventions in Autism (Lord et al., 2021).

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List of Tables

Page

Chapter 2 The Adaptation and Development of a Bilingual Parent-Mediated NDBI Program and Translation of Outcome Measures

Chapter 3 Tele-Coaching Parents of Toddlers' 'at Risk' of Autism in the United Arab Emirates using Naturalistic Developmental Behavioural Interventions (NDBI): A Pilot Study

Chapter 4 An Adaptive Parent-Mediated NDBI Program Delivered via Telehealth - A Sequential Multiple Assignment Randomized Trial

Chapter 5 Parents' Attitude and Engagement in a Brief Adaptive Parent-Mediated NDBI Delivered via Telehealth

Chapter 6 Effective Implementation of a Parent-Mediated NDBI delivered via Telehealth in the UAE

List of Figures

Page

Chapter 2 **The Adaptation and Development of a Bilingual Parent-Mediated NDBI Program and Translation of Outcome Measures**

Chapter 3 **Tele-Coaching Parents of Toddlers' 'at Risk' of Autism in the United Arab Emirates using Naturalistic Developmental Behavioural Interventions (NDBI): A Pilot Study**

Chapter 4 An Adaptive Parent-Mediated NDBI Program Delivered via Telehealth - A Sequential Multiple Assignment Randomized Trial

Chapter 6 Effective Implementation of a Parent-Mediated NDBI delivered via Telehealth in the UAE

List of Abbreviations

ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
AEIQ	Attitude and Engagement in Intervention Questionnaire
AFEQ	Autism Family Experience Questionnaire
AFIRM	Autism Focused Intervention Resources and Modules
AIM	Acceptability of Intervention Measure
AJCH	Al Jalila Children's Specialty Hospital
APC	Asynchronous Parent Coaching
APSI	Autism Parenting Stress Index
ASD	Autism Spectrum Disorder
BACB®	Behavior Analyst Certification Board
BRIDGE	Bond, Regulate, Interact, Develop, Guide, Engage
BST	Behaviour Skills Training
CDC	Center for Disease Control and Prevention
DTT	Discrete Trial Training
EIBI	Early Intensive Behaviour Intervention
EPIS	Exploration, Preparation, Implementation, Sustainment
ESDM	Early Start Denver Model
FBA	Functional Behaviour Assessment
FCT	Functional Communication Training
FIM	Feasibility of Intervention Measure
G-CPMI	Group – Coaching Parent Mediated Intervention
IAM	Intervention Appropriateness Measure
I-CPMI	Individual – Coaching Parent Mediated Intervention
JASPER	Joint Attention Symbolic Play Engagement and Regulation
M	Modules only
M+APC	Modules in addition to Asynchronous Parent Coaching
M-CHAT	Modified Checklist for Autism in Toddlers
NDBI	Naturalistic Developmental Behaviour Intervention
PBC	Perceived Behavioural Control
PE	Psychoeducation
P-ESDM	Parent-Early Start Denver Model
PRT	Pivotal Response Training
R	Responder to intervention
RCT	Randomized Control Trial
RRBI	Restrictive Repetitive Behaviours and Interests
R-SPC	Rescue Synchronous Parent Coaching
SCC-R	Social Communication Checklist-Revised
SMART	Sequential Multiple Assignment Randomized Trials
SR	Slow Responder to intervention
SS	Status Survey
TARF	Treatment Acceptability Rating Form
TPB	Theory of Planned Behaviour
UAE	United Arab Emirates
W-SPC	Weekly Synchronous Parent Coaching

Chapter 1

Introduction

Autism Spectrum Disorder is a neurodevelopmental disability that manifests during childhood and is typically lifelong. Autism is heterogenous and can be associated with a wide range of social, communication, and developmental difficulties and outcomes. The rise in autism diagnoses since the 1990s is a phenomenon of high-income countries, particularly those in North America and Europe (Russell, 2021). The rise in the provision of a diagnosis of autism is generally agreed to be largely artefactual. Russell (2021) has addressed this stating that an autism diagnosis “has been extended to types of people it was almost never applied to before 1990.”

Early identification of the behavioural characteristics of autism and effective intervention to address these, can support autistic children’s developmental trajectories over multiple domains (Rogers & Talbott, 2016; Wergeland et al., 2022). A growing number of efficacious early interventions has been identified in recent decades. It is clear from such research outcomes the importance of a family-centric, strengths-based approach, most notably during the early formative years (Schreibman et al., 2015; Rieth, 2022).

This chapter considers early identification and intervention in autistic children, with a focus on using telehealth technologies in the coaching of parent-mediated early intervention for toddlers (18-36 months), either showing indications of autistic symptomatology or presenting with an established diagnosis. The chapter also provides a discussion of the potential implementation of telehealth coaching with parents located in the United Arab Emirates.

In navigating the complex discourse surrounding Autism Spectrum Disorder (ASD) within this thesis, a deliberate and nuanced approach is adopted, incorporating both identify-first and person-first language interchangeably, with the aim of fostering inclusivity, acknowledging the diverse preferences within the autistic community, and promoting a comprehensive understanding of the multifaceted aspects inherent in the lived experiences of individuals with ASD.

Early Identification and Intervention

Autism Spectrum Disorder (ASD) is defined as “a complex neurodevelopmental disorder characterised by deficits in social interaction and communication, as well as restrictive and repetitive behaviours and interests” (American Psychiatric Association, 2013). The latest report from the Center for Disease Control and Prevention (CDC) it was estimated that 1 in 36 children in a U.S. population study of 8-year-old children were autistic (Maenner et al., 2023).

Children with autism often present with difficulties in social communication and joint attention, apparent in early childhood and often first noticed by parents. It has been established that best practice in early intervention for autistic children involves strategies based on the principles of Applied Behaviour Analysis (ABA). ABA is a science that involves systematically applying the principles of behaviour to improve socially significant behaviours (Cooper, Heron & Heward, 2007). Teaching strategies derived from ABA have been identified as Evidence Based Practice, for example, Early Intensive Behaviour Intervention (EIBI), Discrete Trial Training (DTT), Pivotal Response Training (PRT) and Functional Behaviour Assessment (FBA) among others (Hume et al., 2021; Wong et al., 2014). In fact, the scientific foundation that has gained the greatest level of empirical support as an internationally recognised and well-established therapy for autistic children is EIBI (Reichow, Hume, Barton & Boyd, 2018). Early Intensive Behaviour Intervention provides a comprehensive approach based on the principles of ABA, focusing on a child acquiring cognitive and adaptive behaviours (e.g., language, play, social interaction, imitation, motor skills etc.) and, where necessary, in reducing problematic behaviours that may be detrimental to a person's quality of life and learning potential. This is in concert with incorporating parent training, and supporting transitions into naturalistic environments (i.e., everyday life), in order to achieve generalisation and a positive spill over into everyday life and living (Healy & Lydon, 2013).

Early intervention research has recommended that children diagnosed with autism receive 25 hours per week of active engagement in intensive intervention that is developmentally appropriate, with an emphasis on the importance of parental involvement to enhance generalisation (NRC, 2001, Wetherby et al., 2014, Schreibman et al., 2015).

There has been a growing research interest in the earlier detection of autism in infants and toddlers, and a corresponding need for research in earlier intervention (French & Kennedy, 2018). It is believed that the second year of life is particularly critical in development due to dynamic brain growth and neural plasticity, as well as being a period associated with regression of skills in autistic children (Zwaigenbaum et al., 2015).

The goal of early autism screening is earlier treatment (Rogers et al., 2014). Methods for early intervention have been researched to date and point to the effectiveness of behavioural intervention specifically (see above). There is, however, limited research to date investigating interventions for infants younger than the age of 16 months. Rogers and colleagues (2014) piloted a developmental behavioural intervention which saw promising positive outcomes in this age group. The efficacy of such interventions that meet the needs of toddlers indicating autism or diagnosed as autistic has emerged only recently.

Dawson and colleagues (2010) undertook a small randomised, controlled trial in which they demonstrated the efficacy of a comprehensive developmental behavioural intervention for autistic toddlers (between 18 and 30 months at commencement of the two-year study) in significantly improving cognitive and adaptive behaviour; underscoring the importance of early detection of, and intervention in young autistic children.

Children who are identified before the age of three years and begin receiving early intervention services show more positive outcomes than comparable cohorts of children diagnosed later (Pierce et al., 2016). In addition, follow-up studies from very early intervention research on infants and toddlers diagnosed with, or at-risk of, ASD have shown sustained improvements (in social, communication domains and in adaptive behaviour and cognition (Estes, Munson, Rogers, Greenson, Winter & Dawson, 2015; Green et al., 2017), in keeping with similar findings by Pickles et al (2016) of a cohort of children in middle childhood.

Best practice for interventions for children below the age of three years with suspected or confirmed autism is to include behavioural and developmental approaches as early as possible, and ensure active involvement of parents (e.g., Zwaigenbaum et al., 2015). Indeed, the growing body of evidence on autism intervention during the early childhood period have brought together the fields of behavioural and developmental research and interventions in the field of autism studies. These Naturalistic Developmental Behaviour Interventions (NDBIs) integrate the principles of both Applied Behaviour Analysis and developmental science resulting in substantial and accelerated child learning and behaviour change and appear particularly well suited to the infant and toddler autism population. (Schreibman et al., 2015).

Naturalistic Developmental Behavioural Interventions (NDBI)

Naturalistic Developmental Behaviour Interventions (NDBIs) focus on developmentally based learning goals and important foundational social learning skills known to facilitate acquisition of language and other higher order skills. This group of interventions are implemented in natural everyday settings where learning opportunities can be embedded, utilising natural contingencies, and teaching developmentally appropriate and pre-requisite skills specifically during play and daily life activities (Schreibman et al., 2015).

NDBI models include interventions such as Pivotal Response Training (PRT); Early Start Denver Model (ESDM), Project ImPACT, and Joint Attention Symbolic Play Engagement and Regulation (JASPER). Whereas some of these NDBI models are comprehensive interventions that target many domains (e.g., communication, cognitive, motor, adaptive etc.), such as ESDM; others are considered focused interventions addressing a specific developmental domain (e.g., social communication), such as JASPER. While these models may have technical differences, they each share the same core components and have many common features (Schreibman et al., 2015).

A growing body of research in NDBIs has demonstrated positive effects including improvements in cognitive, linguistic, and adaptive behaviours, as well as reduced severity of symptoms of ASD in toddlers (Dawson et al., 2010; Estes et al., 2015). However, more larger scale studies are needed to elucidate the active ‘ingredients’ of these interventions, and the components that have the strongest effect on outcomes (French & Kennedy, 2018; Zwaigenbaum et al., 2015).

Shreibman et al. (2015) described the core components of NDBIs as falling into three general areas. First, is the ‘nature of learning targets’, which often includes teaching skills and integrating learning across a range of developmental domains during daily interactions and routines with multiple people and materials, rather than targeting skills discretely in isolation. By targeting foundational skills that are precursors of developmental achievements (e.g., joint attention, imitation), a strong learning infrastructure emerges. Second, is the ‘nature of the learning contexts’, which emphasises embedding learning into activities that involve meaningful social engagement and experiencing natural contingencies through play routines or daily life routines (e.g., bath time). Third, the ‘nature of the development-enhancing strategies’, which describes incorporating behavioural strategies (e.g., modelling, shaping, chaining, prompting, reinforcement) to systematically expand a child’s skills while scaffolding age-appropriate skills within daily activities and routines.

NDBI models share several evidence-based features incorporating established paradigms and principles of ABA such as operant-based learning or employing the three-part contingency (antecedent-response-consequence) (Schreibman et al. (2015). NDBI models all ensure ongoing measurement of progress using different data collection methods and using these data to guide intervention goals; another common feature across NDBIs being the use of prompting and prompt fading techniques systematically to evoke behaviours outside of a child’s current repertoire. NDBI models also include individualised treatment goals and the use of natural intrinsic reinforcement. During interactions, the environment is set up to promote child initiation (e.g., blocking access to a toy) and the adult follows the child’s lead while balancing turns or sharing control of the interaction and incorporating modelling and imitation of target skills. In addition, all NDBI models have intervention manuals and fidelity measures to help with consistency of implementation and training for parents.

Parent-Mediated Intervention

A crucial element in the success of early intervention is parental involvement, which facilitates generalisation of skills as well as maximising positive outcomes (Turner, Stone, Pozdol & Coonro, 2006; Healy & Lydon, 2013). Parent-mediated or parent-implemented intervention is an approach whereby professionals support parents in fostering their children's learning and development across natural everyday activities, such as, during mealtimes, dressing, playing, bath time and bedtime routines. Parent-mediated intervention builds on parental competence and confidence in enhancing their child's development (Tomeny et al., 2019).

By embedding intervention strategies in naturally occurring daily activities and play, the opportunity for intervention is maximised (Wetherby et al., 2018). This modality of intervention has gained increased attention in the past decade, with a growing body of research examining its effectiveness for young children with early indications of autism (Tomeny et al., 2019). Research has shown positive outcomes for children, with indications of autism or a received diagnosis, and their parents, including improved joint engagement (Kasari, Gulsrud, Paparella, Hellemann & Berry, 2015), social communication skills (Wetherby et al., 2014), and reduced parental stress levels (Estes et al., 2014). In addition, parent-mediated intervention was reported to lead to better generalisation and maintenance of skills compared to therapist implemented intervention (Koegel et al., 1982).

Supporting parents in implementing established and effective intervention strategies to promote active engagement as early as possible may potentially impact the child's developmental trajectory. Indeed, parent-mediated intervention was reported to meet criteria for evidence-based practice (Hume et al, 2021; Wong et al., 2015). More specifically, in a recent systematic review by Pacia et al. (2021), it was reported that parent-mediated intervention packages based on NDBIs, including PRT, ESDM, and JASPER, were established as evidence-based practice for young autistic children.

Involving parents in the development of goals for their child's development and embedding effective intervention strategies in their daily routine is considered best practice in the field of early intervention. Successful parent-mediated intervention models involve professionals supporting parents to facilitate their child's learning through an approach called *coaching*. This is an interactive process that aims to integrate new information and skills with current ones by building on the parent's own ideas, experience, and knowledge through collaboration and reflective practices (Tomeny et al., 2019; Vismara & Rogers, 2018).

Tomeny et al. (2019) described four components which they found important in successful coaching of parents. Firstly, '*collaborative planning'*, whereby both professionals and parents decide mutually what they will work on during the session. Secondly, '*building on parents' competence'* by supporting them to increase their skills and knowledge. Thirdly, '*guided practice'* through providing opportunities to use their skills and to provide iterative feedback. Fourthly, '*collaborative reflection'* and decision making through discussing parent experience and agreeing on goals and solutions together. These four components chime with Wetherby and colleagues (2018) who emphasise in order to steer away from passive learning, professionals should coach parents through building consensus on targets; practising with support; repetition to increase competence following feedback; and reflection and problem solving with parent led planning. By adopting these coaching strategies, professionals can support parents to influence their child's early years of development and become more proficient agents of change as their child's first and most natural teacher.

In addition to incorporating successful coaching strategies, it is important to consider a parent’s self-efficacy when implementing a parent-mediated intervention. Parent self-efficacy, which is the parents’ beliefs in their ability to successfully parent their child, can have an impact on parental stress, as well as outcomes related to parent/child relationship, and child development as it can also influence the successful implementation of intervention strategies (Russell & Ingersoll, 2021).

Barriers to Early Intervention

While there is strong evidence supporting early intervention in significantly increasing chances for positive outcomes, as well as reducing the lifetime associated societal costs, there are major barriers that prevent young children from accessing evidence based early intervention (Wetherby et al., 2018). Indeed, there is an increasingly wide gap between available resources and demand generated by the increased prevalence of autism (Neely, Rispoli, Gerow, Hong & Hagan-Burke, 2017). Further, this increased demand for services has also contributed to a surge in waitlists for ASD diagnostic evaluations, with wait times from first noticing indications to diagnoses reaching years in some countries (Kunze et al, 2021). In fact, whilst ASD has been reported to be reliably diagnosed as early as 14 months (Pierce et al., 2019), in the United States the average age reported for diagnosis is four years old.

A delay in receiving diagnosis, typically required in order to receive services, ultimately leads to a knock-on prevention of, or long delay in, access to early intervention. This ‘diagnosis first, intervention second’ model is considered a major barrier in very early intervention for toddlers who indicate a potential autism diagnosis.

Compounding this, the average time-delay between a confirmed diagnosis and receiving early intensive behaviour intervention in the community is estimated to be

3 years, with the younger the child is at diagnosis, the longer the time-delay to access services (Wainer, Arnold, Leonczyk & Valluripalli Soorya, 2021).

The service-need gap is further exacerbated by the shortage of appropriately trained professionals in evidence-based behaviour interventions, which results in long waitlists for these services and, in turn, a delayed access to, or denial of, effective early intervention. The National Research Council in the U.S. recommends 25 hours per week of intervention (NRC, 2001), the intensity of clinician time required rendering it even more difficult for most community-based early intervention systems to deliver adequate, appropriate early intervention. Furthermore, for autistic children and their families, available and limited state funding, and family finances for evidence-based behaviour interventions, can present a barrier. In Europe, it is estimated that only one-third of autistic children currently access behavioural interventions (Ferguson, Craig & Dounavi, 2019).

For families living in rural areas, these, and other barriers (e.g., limited or no internet access) are further magnified due to the lack of local service providers, and financial and time burdens of travelling long distances to avail of these services (Ferguson et al., 2019). Given the service-need gap, it is prudent to consider alternative models for the successful delivery of evidence-based intervention to toddlers, indicating or diagnosed as autistic, whose families have limited access to services during this key developmental period.

Bridging the gaps using Telehealth

Telehealth is a model of delivering therapeutic services remotely, using live streaming or online platforms, allowing individuals to receive professional services regardless of geographical location. Utilising a telehealth model for delivery of early Intervention and parental training can allow for families to receive services in a more timely manner, in the child's natural setting, and may enhance the quality of services available to families living in remote areas (Boisvert & Hall, 2014). Telehealth delivery may also facilitate accessing services and harnessing precious time during the crucial early years of neurodevelopment at a time of greater brain plasticity of younger neural systems (Bryson et al., 2007; Ozonoff et al. 2010). Recently, telehealth-based tools, including the Naturalistic Observation Diagnosis Assessment-Enhanced, has been demonstrated to be a valid and reliable tool for the assessment and diagnosis of ASD through the evaluation of synchronous and asynchronous behaviours (Morrier et al., 2023).

One way to narrow the service-need gap and increase the availability of empirically supported interventions for young autistic children is through telehealth. Telehealth is a model of delivering therapeutic services at a distance, using live streaming or online platforms, allowing individuals to receive professional services regardless of geographical location. Utilising telehealth as a delivery model to provide early intervention and to support parent training can enable families to receive services in a timely and cost-effective manner in the child's natural setting and may thus enhance the quality of services available to families living in remote areas (Boisvert & Hall, 2014).

Ferguson and colleagues (2018) reported that telehealth was shown to be an effective and feasible platform in increasing both parent's knowledge and implementation of skills based on behaviour analytic interventions. There is evidence suggesting that remote supported parent-mediated interventions may improve social and communication skills of their autistic children (Parsons, Cordier, Vaz & Lee, 2017). In addition, this model of service delivery has been perceived positively by parents of young autistic children (Vismara & Rogers, 2012; Wainer & Ingersoll, 2015).

The delivery of telehealth-based interventions for autistic children has been reported by recent research studies that investigated a variety of formats. One such delivery method is though self-directed parent training programs in NDBIs. While this can offer flexibility and be a scalable and cost-effective format that is acceptable to parents, it has been reported to have some limitations, including time barriers to participation, decreased parent engagement, and decreased likelihood of reporting gains in child skills compared to coaching by a professional (Ingersoll & Berger, 2015). Another format examined by Bearss and colleagues (2018), was ‘real-time’ or synchronous videoconferencing to deliver parent training or coaching to support parent-mediated intervention for autistic children which was suggested to have high rates of fidelity, parent engagement, and reported positive outcomes. While these data are promising, solely utilising a parent coaching format requires an intensive amount of clinician time and does not address the significant barrier of a shortage of trained professionals (Wainer et al., 2021).

Integrating both self-directed and parent coaching formats can be a more effective approach to using telehealth in parent-mediated interventions, as the parent can both access learning content at their own pace and then also connect with a professional to receive coaching (Wainer et al., 2014). This ‘hybrid’ approach was reported by Ingersoll and Berger (2015) to have increased parent implementation fidelity, increased positive perception of the child and greater positive outcomes, compared to self-directed learning alone. In a review by Neely and colleagues (2017) their findings indicated increased fidelity in implementation of intervention for autistic children following training via telehealth which included a combination of on-line modules in addition to performance feedback-based coaching. Therefore, while information and education can be provided through group based or self-directed platforms, an individual parent coaching component is likely an active ‘ingredient’ optimising positive outcomes (Wetherby et al., 2018).

To further explore a more individualised model for the delivery of parent-mediated NDBI using telehealth, Wainer and colleagues (2021) studied an adaptive intervention, whereby a stepped-care approach was followed through offering less intensive intervention as a first-line treatment and intensifying the intervention when clinically indicated. This approach showed strong acceptability, improved parent fidelity of intervention, and improved self-efficacy.

In regard to therapeutic self-efficacy in the implementation of parent-mediated interventions through telehealth, Russell and Ingersoll (2021) reported, for a cohort of parents of young autistic children, a positive association between higher levels of parental self-efficacy and both utilising effective strategies and more efficacious learning.

Parent-mediated NDBIs delivered via telehealth incorporates evidence-based approaches in a naturalistic environment while reducing professional time and accelerating cost-effective access to very early intervention, allowing for immediate response as soon as toddlers show indications of autism. Pacia and colleagues (2021) reported treatment effects for telehealth delivery of parent-mediated intervention to be similar to face-to-face delivery, which positions telehealth as a promising solution to expand the reach of evidence-based interventions.

While the main focus of NDBIs is the acquisition of skills related to social communication and interaction, including, joint attention, play, communication, and imitation, they do not directly target Restrictive Repetitive Rehaviours and Interests (RRBI) associated with ASD. RRBIs, including inflexibility, lack of variability, limited responsiveness, and intense interest in highly preferred items, can sometimes present a challenge to children creating a barrier to social interaction and learning new skills. In a study by Kunze, Machalicek, Wei and St Joseph (2021) parents were successfully coached via telehealth to target inflexible RRBIs in toddlers with early indications of ASD through play using evidence-based ABA strategies, and an overall decrease in inflexibility and RRBI was reported.

ASD in the context of the United Arab Emirates

The United Arab Emirates (UAE) is a Muslim country located in the Middle Eastern region (Western Asia) and is made up of seven Emirates. The ethnically diverse population of the UAE was most recently estimated to be 9.9 million (World Bank, 2021). Emirati citizens account for 11% of the population, while expatriates and immigrants make up the remaining 89%. Around two-thirds of the population live in the main cities of Dubai, Abu Dhabi, and Sharjah, while the rest populate less urbanised cities (CIA Factbook, 2021).

There is a paucity of recent epidemiology studies of ASD prevalence in the UAE. The prevalence of Pervasive Developmental Disorder in the UAE has been reported to be 29 in 10,000 according to a study by Eapen et al. (2007). Whilst this figure is considerably lower than international prevalence rates, actual prevalence of ASD in the UAE is believed to be similar to international estimated rates.

In the UAE, ASD is considered as one of the major challenges in the healthcare, educational and social services sectors. Limited resources have contributed to long waiting lists for ASD diagnostic assessments, which in turn delays early intervention and subsequent positive outcomes. In the UAE, parents perceive the wait time for diagnostic assessments to be too long (up to 8 months from first recognising indications), with most children not receiving any form of early intervention before the age of four years (Mahmoud, 2017). In addition, early intervention is often delayed due to families needing diagnostic reports in order to access resources. (Personal communication, Al Jalila Children's Specialty Hospital, 2019).

Policies and legislations specific to Autism are still in their infancy in the UAE. Recently, in April 2021, the UAE cabinet approved 'The National Policy for Autism' (UAE Ministry of Community Development, 2023). This policy is built on five pillars, which are, Diagnosis; Healthcare; Human Resources; Education Inclusion; and Awareness and Community Empowerment. While this represents a positive step towards improving the quality of life of autistic children and their families, there remains a gap between policy and practice. There are currently no formal pathways or national guidelines for the diagnosis of autism and interventions in the UAE. The majority of families seeking diagnostic evaluations or early interventions resort to the private sector for clinical services, with nationals from certain Emirates, including Dubai, receiving financial support from governmental health entities to seek early intervention, specifically ABA, in private clinics for children below six years of age that are diagnosed as autistic (Personal communication, Al Jalila Children's Specialty Hospital, 2019).

There are currently four government established Autism centres in the UAE that provide intervention and rehabilitative services. These are located in the three main cities of the UAE, and mostly provide rehabilitative services and supports for children over 3 years old - with only one centre specifically providing structured ABA by licensed professionals. Within the community space, there are several private clinics that provide early intervention services including unstructured behaviour-based approaches, Speech and Language Therapy, Occupational Therapy, and Special Education support, and ABA. However, professionals licensed to provide ABA intervention services are mostly located in the three main cities of the UAE (Dubai, Abu Dhabi, Sharjah).

Evidence based therapeutic services for autistic children include recommendations for EIBI, which are provided by licensed ABA professionals including a team of Behaviour Analysts and Behaviour Technicians. There are currently a total of 203 active Behaviour Analysts registered under the Behavior Analyst Certification Board (BACB®) in the whole of the UAE (BACB, October 1st, 2023). The lack of licensed professionals likely puts further strain on the capacity for the provision of effective early intervention practices.

Delivering Parent-Mediated NDBI via Telehealth in the UAE

Interventions for children younger than three years with either indications or diagnosis of ASD are recommended to consider sociocultural beliefs of the family, and further research is needed to include culturally diverse populations to evaluate factors that may affect participation, acceptability, and outcomes (Zwaigenbaum et al., 2015).

In the UAE, there are long wait lists for diagnostic evaluations and limited early intervention services provided for toddlers indicating or diagnosed with ASD. Further, there is a lack of service provisions in less urbanised cities or remote areas of the UAE.

In the last decade, the UAE has grown to be the most technology-friendly country in the Middle East, with almost 99% of the population being active internet users (The World Bank, May 17th, 2021). Parent coaching using telehealth can offer a convenient solution that can ease the financial burden and reduce travel time associated with accessing intervention. The impact can be particularly significant for non-urban areas that lack high quality evidence-based services or families with financial limitations. Exploring the provision of telehealth coaching in the delivery of parent-mediated early intervention for autistic toddlers through research protocols is warranted. This will enable researchers and clinicians to establish optimal means of knowledge dissemination and skill acquisition among parents as primary carers and interventionists with their child.

Chapter 2

The Adaptation and Development of a Bilingual Parent-Mediated NDBI Program and Translation of Outcome Measures

In Chapter 1 the current evidence base for Naturalistic Developmental Behavioural Interventions (NDBI) was described, with a focus on how telehealth can be utilised to expand its reach through coaching of parent-mediated interventions. The limited available resources in the UAE, and the challenges this presents for early identification and intervention for young children with ASD were also discussed.

NDBI programs have been heavily researched to date in non-representative populations. They are conspicuously developed in high-income countries and designed to fit their cultural context (Nielsen et al., 2017). When implementing NDBIs in low-resource contexts, such as the case in the UAE, it is important to consider and understand key factors, including: the 'natural' context in which the intervention occurs; the social validity of the developmental and behavioural targets to be taught within a specific cultural or contextual setting; as well as the cultural and contextual validity of outcome tools used to measure the effectiveness of the intervention delivered (Schlebusch et al., 2020).

In planning intervention within a specific setting, it is important to consider implementation science theory to ensure effective implementation of the intervention. This includes the careful consideration of who will be delivering the intervention, where the intervention will take place, what is the process and provisions for planning implementation of the intervention, as well as, what the identified barriers and facilitators in implementation are and how can the intervention be adapted (Schlebusch et al. 2020). Finally, in pragmatically evaluating implementation and effectiveness of interventions, implementation science theory suggests the use of a mixed-methods approach (Palinkas et al., 2011) and considering implementation outcomes, fidelity outcomes, and intervention outcomes (Schlebusch et al., 2020).

In this chapter, we describe the process undertaken in adapting and developing a contextually fit parent mediated NDBI program delivered via telehealth, drawing from implementation science theory. Specifically, how experience from a brief pilot trial during the COVID-19 pandemic informed the process of planning the intervention and gave an initial understanding of the local context of the UAE setting and potential barriers and facilitators in implementing the intervention. The process and provisions taken in adaptation and evaluation of intervention will also be discussed, including developing the content of the intervention in both English and Arabic language, and translation of outcome measures used into Arabic.

The Early Start Denver Model

The Early Start Denver Model (ESDM) is an evidence based manualised NDBI designed for children between the age of 18-48 months. The curriculum is designed to target core symptoms of ASD and different developmental areas based on the combined principles of ABA and developmental psychology (Dawson et al., 2010). The effectiveness of the ESDM has been documented in several studies, specifically in improving intellectual functioning, adaptive behaviours, language, and severity of ASD symptoms (Dawson et al., 2010; Estes et al., 2015; Vivanti et al., 2016). The ESDM curriculum also includes a parent-mediated version (P-ESDM), whereby parents implement intervention strategies in daily activities to maximise learning potential in children with ASD (Vismara & Rogers, 2018; Rogers et al., 2014;), which has also been delivered via telehealth (Vismara et al., 2012). P-ESDM intervention covers a range of topics including: the principles of learning and behaviour; promoting parent-child engagement; use of sensory social routines; promoting joint attention; enhancing verbal and non-verbal communication; developing imitation skills; and building functional and symbolic play (Rogers & Dawson, 2012). Studies investigating P-ESDM report significant improvements in parent stress, parent sense of competence, as well as child development (Estes et al., 2014; Vismara & Rogers, 2018). Implementation of telehealth delivered P-ESDM was also investigated in South Korea, with promising feasibility and effectiveness (Kim et al., 2022).

The utility of P-ESDM in non-westernised/English speaking countries is important to consider when choosing an NDBI model to implement within the context of the UAE. In addition to its demonstrated efficacy and feasibility, and its manualised curriculum that incorporates the fundamental principles of NDBI, the ESDM parent handbook (Rogers, Dawson, & Vismara, 2012) is also available translated into the Arabic language (Rogers, Dawson, & Vismara, 2012/2022). This further facilitates the transfer of knowledge in a predominantly Arabic speaking country, such as the UAE, and was therefore chosen as the curriculum to base our current NDBI intervention and research program on.

Training of Facilitator in NDBI Intervention

The main facilitator of the parent-mediated NDBI program, and primary investigator of the research program, was a bilingual (English/Arabic) licensed behaviour analyst with over eight years of experience working directly with children with ASD and their families. An introductory course workshop in the Early Start Denver Model was completed in 2018 with University of California (UC) – Davis, MIND Institute. This was a pre-requisite to further training in ESDM.

In 2019, the facilitator attended an ESDM advanced workshop which was held at the Center for Autism Research in Riyadh, Saudi Arabia, and delivered by Dr Sarah Dufek from the UC-Davis MIND Institute. The workshop included hands-on practical training in conducting ESDM skill-based evaluation across developmental domains, building objectives for intervention, implementation of ESDM strategies. Completion of the advanced level workshop was contingent on successful implementation of strategies with 80% fidelity as observed by a trainer. After completion of the workshop, remote post-training supervision was received by Ms. Melissa Mello, a licensed ESDM trainer at the UC-Davis MIND Institute, for a period of five months, as part of the final steps required for certification. This involved remote observation and feedback on direct implementation of assessment and intervention strategies and techniques with patients from Al Jalila Children's Specialty Hospital (AJCH) in Dubai. ESDM certification was not completed due to COVID-19 pandemic restrictions on delivery of direct intervention at the hospital prior to completion of final certification requirements.

It should be noted that the decision to attend the advanced workshop in Saudi Arabia was due to it being the only available site scheduled to deliver an advanced ESDM workshop that year within proximity to the United Arab Emirates. The process for completion of all steps required to become a certified ESDM practitioner typically take six months to one year, with the total cost of training and certification supervision to be around 5000-6000 United States Dollars.

Experience from a Pilot Trial during the COVID-19 Pandemic

In March of 2020, as the COVID-19 pandemic was declared, the United Arab Emirates began enforcing restrictions involving social distancing regulations across different sectors in the country, including the healthcare sector. This resulted in the decision to limit mental health services to be delivered via telehealth. This presented a challenge within the Autism program at AJCH, as diagnostic evaluation services had to be put on hold since they relied on direct observation and interaction. In addition, direct intervention services within the private sector and community-based settings were also restricted in providing services for children diagnosed with ASD. During that time, there was an increasingly large number of young children awaiting diagnostic evaluations, and lack of direct intervention services available during that time. While virtual follow-up appointments were being provided for patients with an established diagnosis of ASD in order to provide parents with support, patients on the ‘wait-list’ for diagnostic assessment were left un-supported while waiting for direct services to resume.

In an effort to provide some support for parents of young children that were ‘at-risk’ of ASD, a small-scale pilot evaluation was initiated by the primary investigator to provide group-based tele-coaching of parent-mediated NDBI. The aim of the intervention program was to coach parents in learning how to help increase their child’s social emotional interactions, communication, and play, through everyday learning opportunities in their natural environment, within a supportive group-based setting. Some of the objectives included, learning techniques to draw their child’s attention to people in their environment; making social play more rewarding and enjoyable for the child; learning how to promote core developmental skills including attending, imitation, verbal and non-verbal communication, joint attention, and shared enjoyment.

A small cohort of four parents of toddlers between the age of 18-36 months identified as ‘at-risk’ of ASD and awaiting diagnostic evaluation at AJCH were invited to participate in the intervention. The parents were invited to join based on their previously expressed interest in receiving support via telehealth during routine follow ups with the clinician. Two of the parents were local Arabic speaking Emirati fathers, one parent was an Arabic speaking mother from another Arab country, and one parent was an English-speaking father from India.

The intervention was offered at no cost to families and involved a 4-week cycle, during which parents were required to attend two group-based sessions per week delivered virtually via Microsoft Teams application. The virtual sessions were held on every Sunday (Session A) and Thursday (Session B). Session A was structured to allow the facilitator to present the weekly topic/theme (in English), based on content from the ESDM parent manual (Rogers and Dawson, 2012). At the end of the session, parents were assigned the task of sending a recorded video demonstration of an interaction with their child implementing the strategies related to that week's theme. Parents were also sent a 'Take home message' summary document of the presentation content. The videos were viewed by the practitioner prior to session B, and upon consent, it was shared with the group during that session. Session B was structured to provide group-based coaching and discussion of examples of each parent's experience in implementing the strategies at home. Table 2.1 below presents a summary of topics covered during the cycle.

Table 2.1

Summary of the content covered in each session for the duration of the four-week cycle of intervention.

Week	Session A	Session B
1	**Planting 'Seeds':** Introduction to program and objectives. How to 'set up' routines at home around play, meals, sleep etc.	Discussion and Coaching
2	**Stepping into your child's Spotlight:** Increasing attention to you, to increase their opportunities to learn.	Discussion and Coaching
3	**Finding the Fun:** Increasing shared enjoyment during sensory social routines. **Talking Bodies:** Providing ways for your child to learn to express needs, feelings, and interests using non-verbal communication and understanding others' body language.	Discussion and Coaching
4	**Building back-and-forth interactions:** Building joint interactions routines and back-and-forth interactions into daily play and caregiving activities to increase engagement and communication. **"Do what I Do!"** Encouraging imitation your childs' sounds, gestures, facial expressions, actions, and words to teach your child to imitate yours.	Discussion and Coaching

Three of the parents completed the intervention and attended all scheduled sessions. One parent withdrew from the intervention due to a misunderstanding about the nature of the session being group-based video conferencing calls, as well as the language on instruction being in English, which they were not comfortable with.

In regard to outcomes of the intervention, no tools or outcome measures were used to collect data. However, parents were asked to complete an open-ended feasibility and acceptability questionnaire at the end of the intervention cycle (Table 2.2), which only two parents out of three completed. Both parents reported that the intervention program was "Extremely helpful" and that they would "highly recommend" it to other parents. Both parents reported that they prefer for the sessions to be group-based and one parent described it as "the second most important aspect, as it allows for exchange of ideas and experiences”. Both parents reported that they were “very comfortable” using a video conferencing application with the video feature ‘on’, and both reported that both telehealth and ‘in person’ delivery would be equally acceptable. Both parents reported the frequency of two times per week to be “acceptable”, although one parent reported that there was not sufficient time between the session A and B to “apply the theories learnt at the start of the week”. In regard to what feature of the program they found to be most helpful, one parent reported that overall, the intervention program was different to anything they tried before and facilitated “better understanding and connecting with the child”, while the other parent found the “presentations and take-home message document” to be most helpful. One parent reported that they prefer to have “more than one hour” for the sessions, as it was “not enough”, the other parent found the pace to be acceptable. Both parents reported that they continued with the intervention program as they were “learning” from the instructor, and that sharing their experiences and listening to other families made them feel less “alone”.

Table 2.2

Questions from the Feasibility and Acceptability open-ended questionnaire shared with parent participants post-intervention.

Q1	How helpful was the ‘Blue Seeds’ program, overall? Would you recommend this program to other parents of children with Social Communication concerns?
Q2	Would you prefer for this program to be delivered via Telehealth or ‘In Person’?
Q3	Would you prefer for this program to be delivered individually or as a ‘group based’ program?
Q4	How comfortable were you using a video-conferencing platform with video on?
Q5	Was the length of cycle (4 weeks) and frequency (2 X/week) acceptable?
Q6	What specific features of the program do you think were the most helpful?
Q7	How did you find the pace of the Instruction Sessions and Coaching sessions? Would you change anything?
Q8	What kept you participating in the program?

The pilot evaluation program conducted during the COVID-19 pandemic provided an opportunity to gain initial feedback from parents of young children identified as ‘at-risk’ of ASD on whether telehealth delivery of parent-mediated NDBI is a feasible and acceptable modality, as well as serve as a proof of concept to facilitate further research. While the intervention was reported to be helpful by parents that completed the four-week cycle and facilitated better understanding of their children and how to interact with them in everyday activities, it is important to understand how to adapt the intervention for contextual fit.

An immediate observation was that one parent withdrew from the intervention due to it being provided in English only. This was a clear barrier for access to intervention. In order to be in line with implementation science theory, and consider cultural and contextual validity, it is important to provide the intervention in both English and Arabic and expand reach. Further, the feedback provided by parents highlighted the importance of allowing more time for parents to practice the strategies learnt in order to benefit further. This can be adapted through increasing the length of intervention cycle, which can allow time to cover less content each week and provide more opportunities for the parents to master the strategies before moving on to the next topic. Further, having pre-recorded video presentations that can be viewed by parents at their own convenience should allow for further flexibility in practicing the strategies learnt.

Finally, in considering the group-based modality of intervention, it is important to note that not all parents may feel equally as comfortable with video conferencing sessions amongst a group of parents. This is especially the case with more conservative local Emirati mothers who might hesitate to switch the video feature on (a cultural consideration), which may compromise the balance and dynamic of sharing experiences comfortably amongst all members. Therefore, it is important to examine this further with a larger sample size that may be more representative of the local context of setting.

Adaptation and Development of Bilingual Modules

Considering the barriers and facilitators experienced from the pilot evaluation, ten pre-recorded video presentations were created based on themes from the ESDM parent manual (Rogers & Dawson, 2012). Each pre-recorded video presentation, or module, included six components:

a) An introduction to the module with objectives (Figure 2.1).

b) Description of how the milestone related to the specific theme presents in typical development compared to children with social communication challenges (Figure 2.2).

c) Guided steps for implementing the teaching strategies related to the theme and the rationale for each step (Figure 2.3).

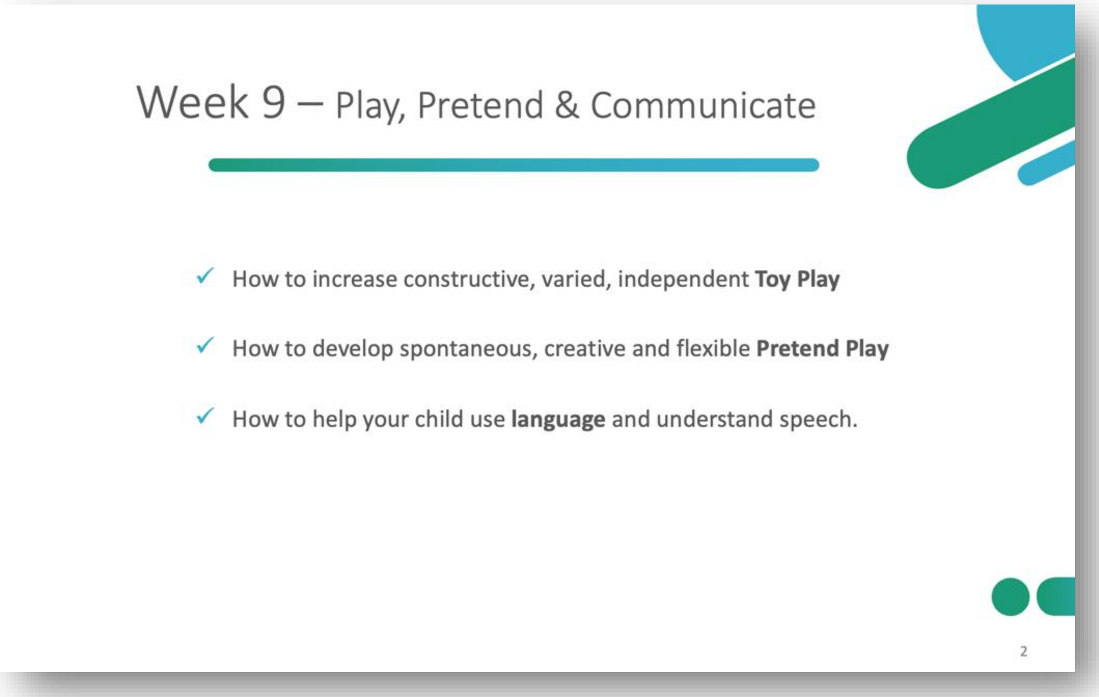
d) Suggested activities to try at home, with examples of how to implement the teaching strategies (Figure 2.4).
e) 'Take home message' with summary of key points from the module.
f) 'Task of the week' which involves parent recording a video of an interaction with their child demonstrating the strategies from the module (Figure 2.5).

The program was given the name '*Blue Seeds'*, whereby 'blue' was a reference to the colour known to be associated with Autism in the UAE, and 'seeds' was a reference to the themes introduced in each module which is comparable to 'planting seeds' that parents can grow with their child for years to come.

The content of the presentations was translated into Arabic and recorded again using Arabic as the language of instruction. A total of twenty pre-recorded video presentations were created, with a duration ranging from 16-28 minutes per module, and total hours of instruction being 208 minutes for the English modules and 217 minutes for the Arabic modules.

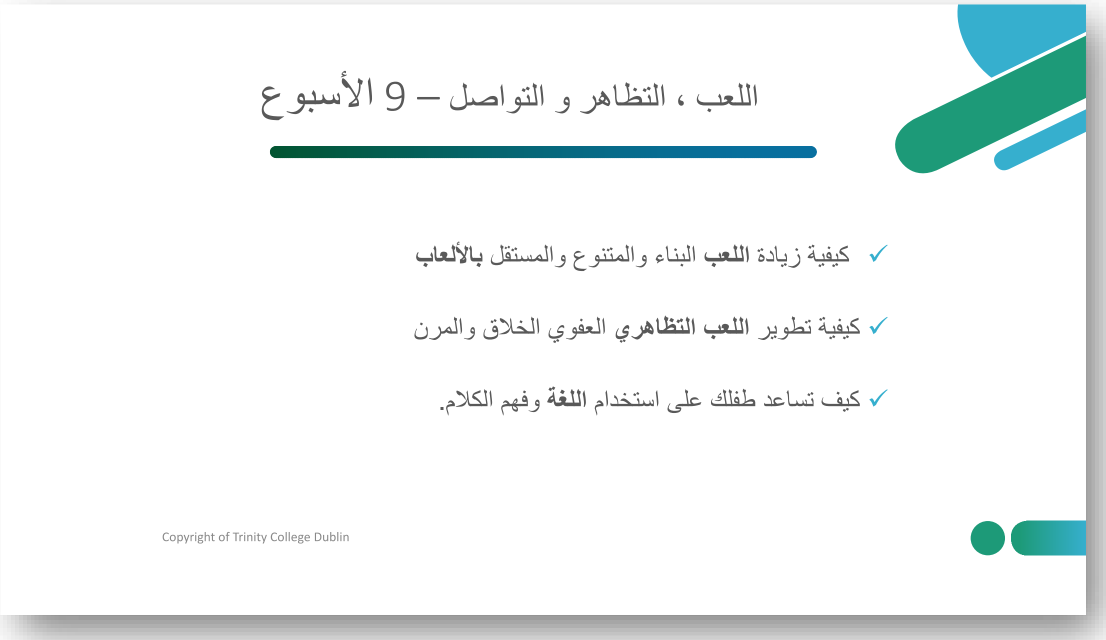
Figure 2.1

Example English and Arabic slides demonstrating the' introduction and objectives' component from module 9 (Play, pretend, and communicate).



Week 9 – Play, Pretend & Communicate

- ✓ How to increase constructive, varied, independent **Toy Play**
- ✓ How to develop spontaneous, creative and flexible **Pretend Play**
- ✓ How to help your child use **language** and understand speech.

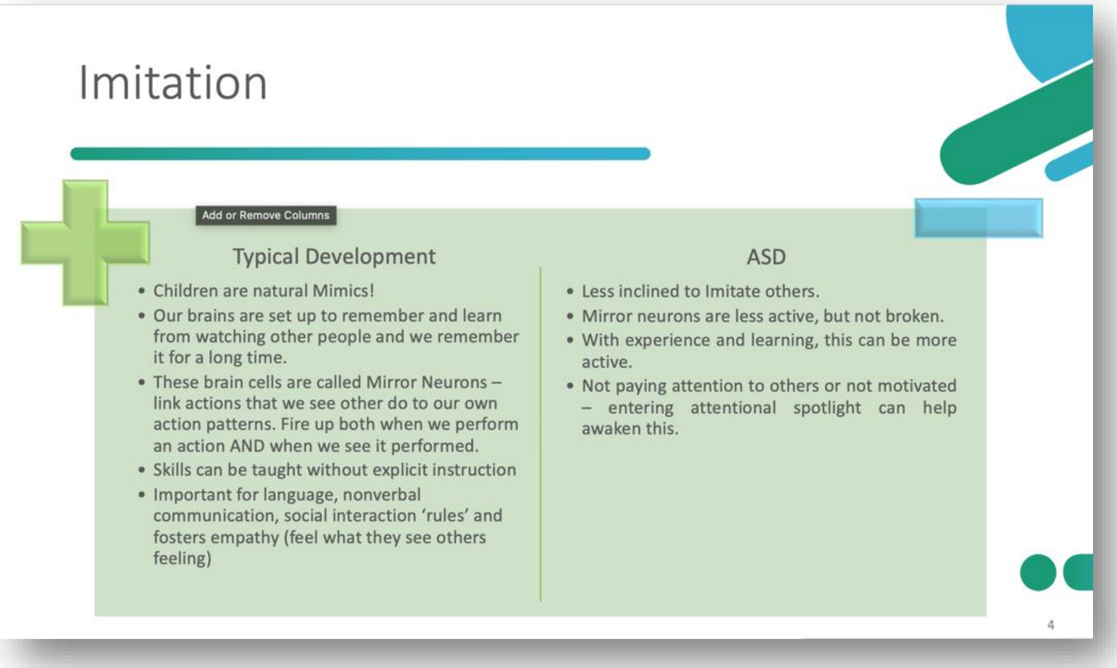


اللعب ، التظاهر و التواصل – 9 الأسبوع

- ✓ كيفية زيادة **اللعب** البناء والمتنوع والمستقل **بالألعاب**
- ✓ كيفية تطوير **اللعب التظاهري** العفوي الخلاق والمرن
- ✓ كيف تساعد طفلك على استخدام **اللغة** وفهم الكلام.

Figure 2.2

Example English and Arabic slides demonstrating the 'developmental milestone description' component from module 6 (Do what I do)



Imitation

Typical Development

- Children are natural Mimics!
- Our brains are set up to remember and learn from watching other people and we remember it for a long time.
- These brain cells are called Mirror Neurons – link actions that we see other do to our own action patterns. Fire up both when we perform an action AND when we see it performed.
- Skills can be taught without explicit instruction
- Important for language, nonverbal communication, social interaction 'rules' and fosters empathy (feel what they see others feeling)

ASD

- Less inclined to Imitate others.
- Mirror neurons are less active, but not broken.
- With experience and learning, this can be more active.
- Not paying attention to others or not motivated – entering attentional spotlight can help awaken this.

التقليد

ذوي صعوبات التواصل و التفاعل

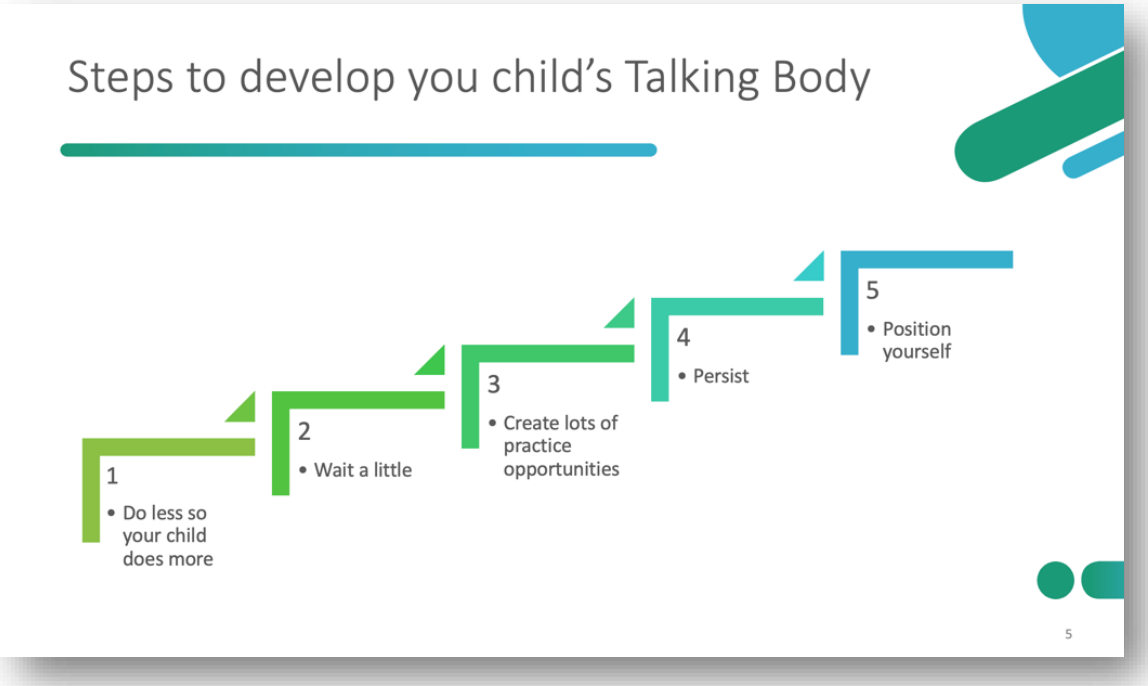
- أقل ميًلا لتقليد الآخرين..
- الخلايا العصبية المرآتية أقل نشاطًا ، لكنها غير مكسورة. .
- مع الخبرة والتعلم ، يمكن أن يكون هذا أكثر نشاطًا
- عدم الالتفات إلى الآخرين أو عدم الدخول في دائرة الضوء المتعمد يمكن أن يساعد في إيقاظ هذا الأمر.

التطور الطبيعي

- الأطفال مقلدون بالفطرة!
- أدمغتنا مهيأة للتذكر والتعلم من مشاهدة الآخرين ونحن نتذكرها لفترة طويلة.
- تسمى خلايا الدماغ هذه الخلايا العصبية العاكسة - تربط الأفعال التي نراها تقوم بها الآخرين بأنماط عملنا. أطلق كلاهما عندما نؤدي إجراءً وعندما نراه يتم تنفيذه.
- يمكن تدريس المهارات دون تعليمات صريحة
- مهم للغة والتواصل غير اللفظي و "قواعد" التفاعل الاجتماعي ويعزز التعاطف (يشعر بما يرونه مشاعر الآخرين)

Figure 2.3

Example English and Arabic slides demonstrating the ‘Guided steps for implementation’ component from module 5 (Talking bodies).



Steps to develop you child’s Talking Body

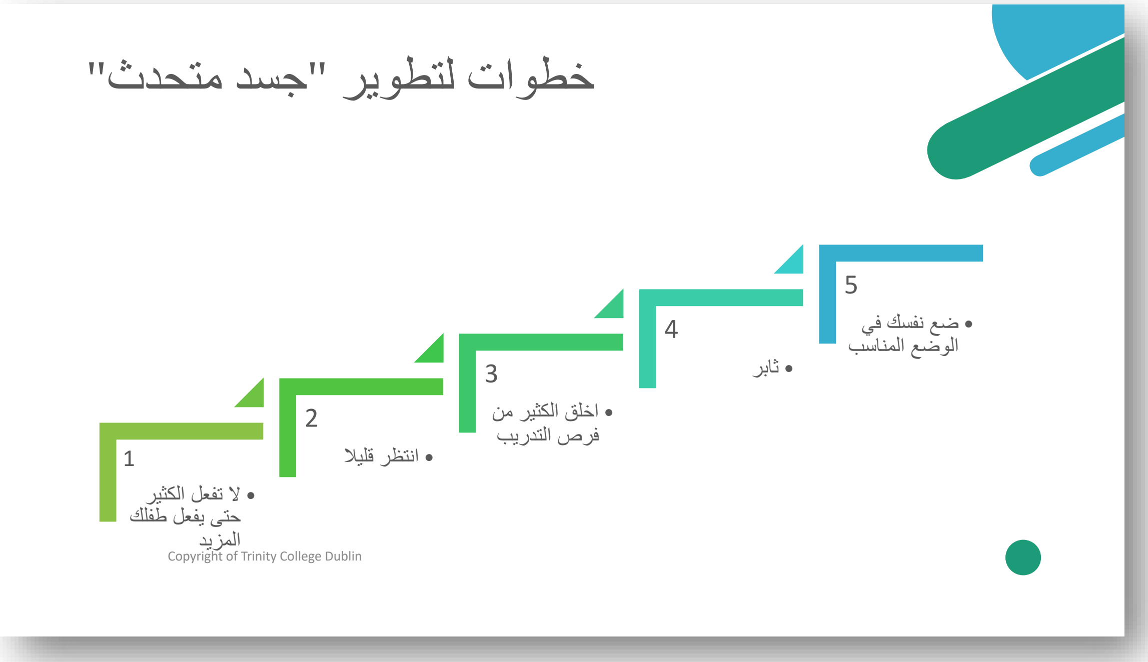
1
- Do less so your child does more

2
- Wait a little

3
- Create lots of practice opportunities

4
- Persist

5
- Position yourself



خطوات لتطوير "جسد متحدث"

1
- لا تفعل الكثير حتى يفعل طفلك المزيد

2
- انتظر قليلا

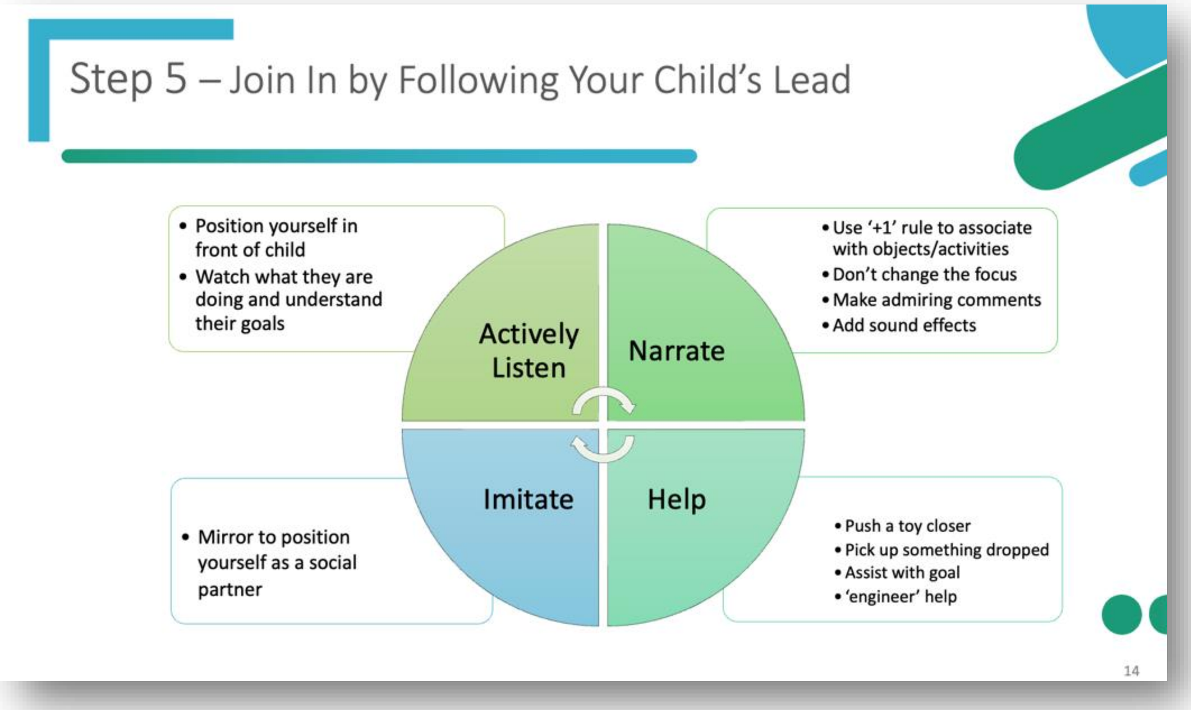
3
- اخلق الكثير من فرص التدريب

4
- ثابر

5
- ضع نفسك في الوضع المناسب

Figure 2.4

Example English and Arabic slides demonstrating the 'suggested activities and examples' component from module 2 (Stepping into your child's spotlight).



Step 5 – Join In by Following Your Child's Lead

- Position yourself in front of child
- Watch what they are doing and understand their goals

Actively Listen

Narrate

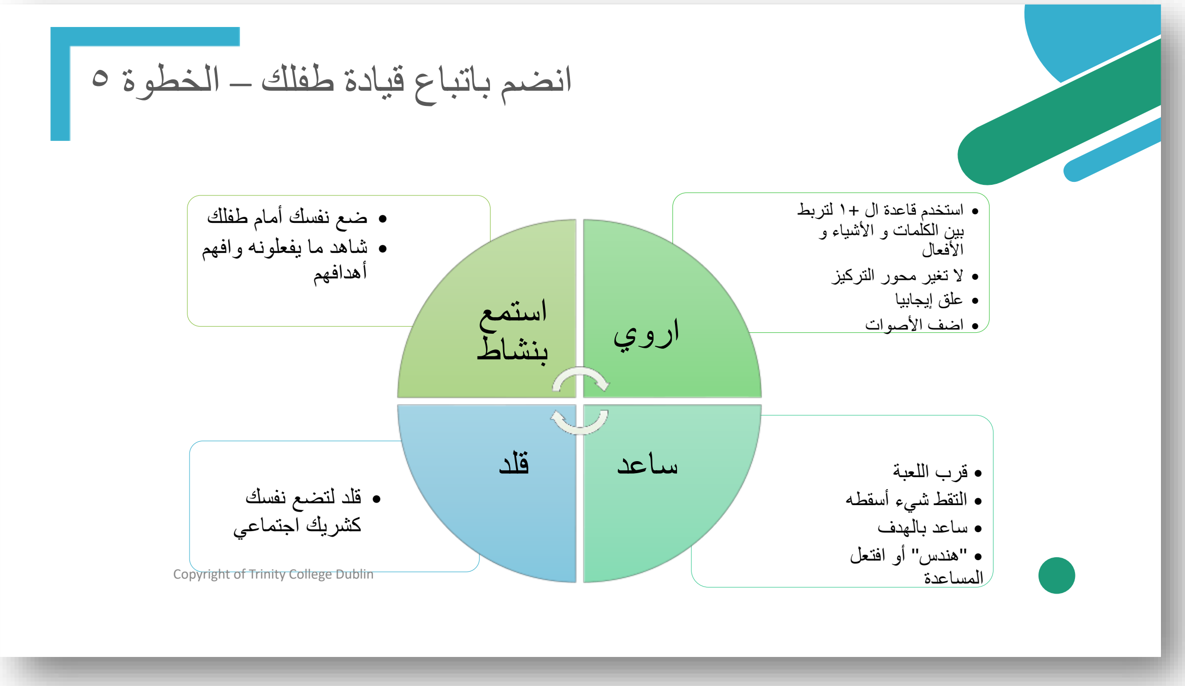
- Use '+1' rule to associate with objects/activities
- Don't change the focus
- Make admiring comments
- Add sound effects

Imitate

Help

- Mirror to position yourself as a social partner

- Push a toy closer
- Pick up something dropped
- Assist with goal
- 'engineer' help



انضم باتباع قيادة طفلك – الخطوة ٥

- ضع نفسك أمام طفلك
- شاهد ما يفعلونه وافهم أهدافهم

استمع بنشاط

اروي

- استخدم قاعدة ال +١ لتربط بين الكلمات و الأشياء و الأفعال
- لا تغير محور التركيز
- علق إيجابيا
- اضف الأصوات

قلد

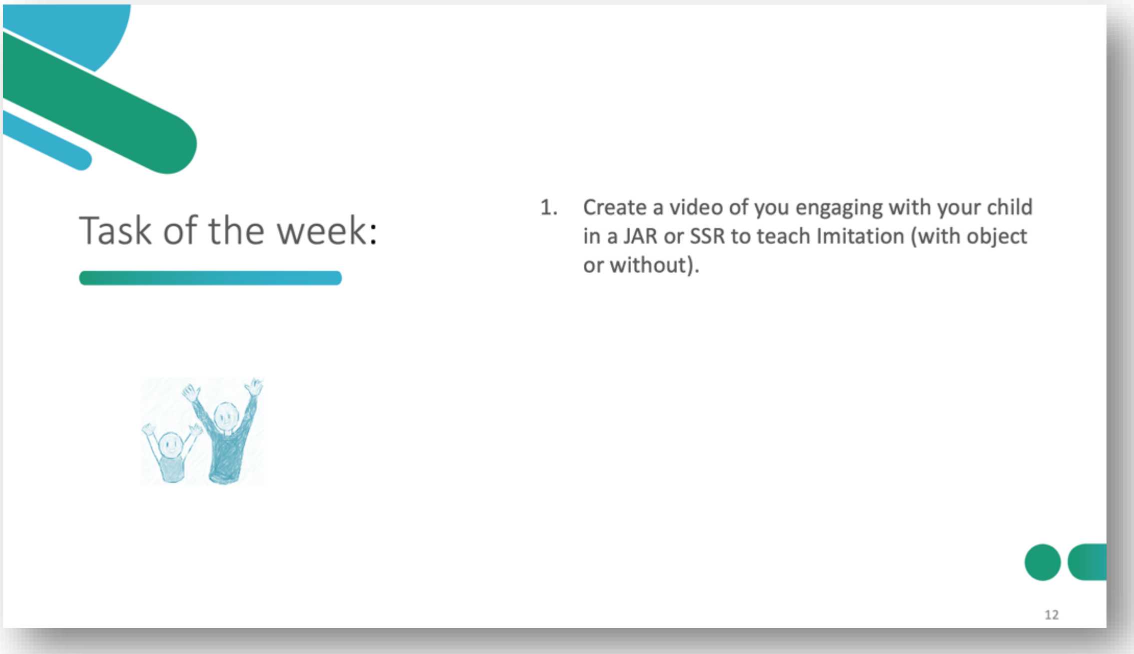
ساعد

- قلد لتضع نفسك كشريك اجتماعي

- قرب اللعبة
- التقط شيء أسقطه
- ساعد بالهدف
- "هندس" أو افتعل المساعدة

Figure 2.5

Example English and Arabic slides demonstrating the 'Task of the week' component from module 6 (Do what I do).



Task of the week:

1. Create a video of you engaging with your child in a JAR or SSR to teach Imitation (with object or without).

نشاط الأسبوع

1. أنشئ مقطع فيديو لك وأنت مندمج مع طفلك في روتين نشاط مشترك أو روتين حسي اجتماعي و تعلمه التقليد باستخدام الخطوات ال ٥

The final module did not cover a specific theme or introduce any new strategies. Instead, it served to conclude how all the strategies learnt can be incorporated together, and how to positively collaborate with professionals in the future if their child needed additional interventions. It also included a final message to parents about the importance of self-care to continue supporting their children, as well as the benefits of sharing these techniques with other family members or caregivers. Table 2.3 presents a summary of the themes and duration of each of the pre-recorded video presentations. Due to the large file size, all recorded presentations will be available to access in a 'Thesis Supplementary Folder' located on a Microsoft Teams shared drive.

Table 2.3

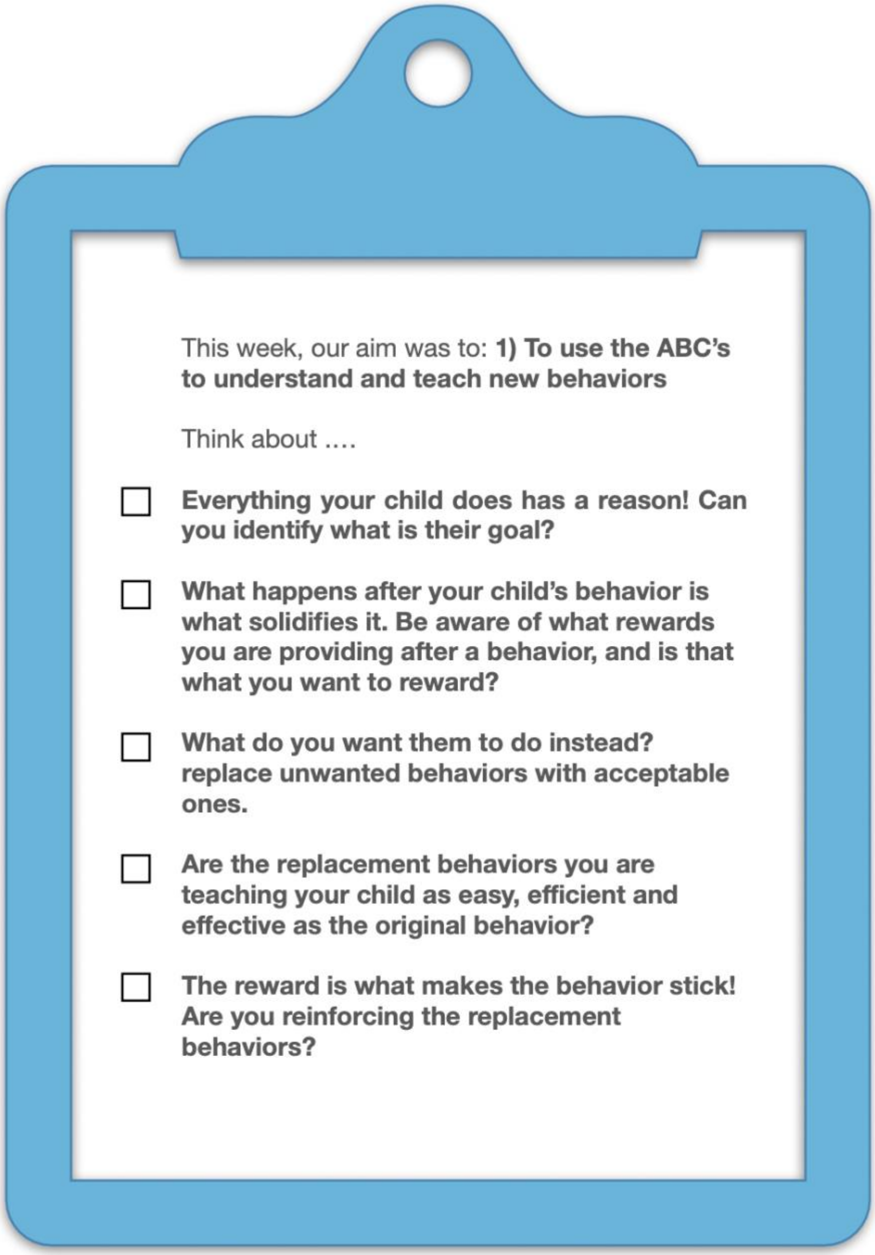
Summary of themes covered in each module and duration of pre-recorded video presentations in minutes for both English and Arabic versions.

Module Number	**Theme**	**Descriptive Summary**	**Duration of video (English)**	**Duration of video (Arabic)**
1	Introduction	Setting the scene at home	28 minutes	26 minutes
2	Stepping into your child's spotlight	Increase attention to you, to increase opportunities to learn	23 minutes	26 minutes
3	Finding the fun	Increase smiles and laughing during sensory social routines	16 minutes	16 minutes
4	It takes two	Building joint interaction routines into daily activities	19 minutes	22 minutes
5	Talking bodies	Using non-verbal communication and understanding others' body language to express interest and feelings	19 minutes	20 minutes
6	Do what I do	Imitating your child's sounds, gestures, actions, and words to teach your child to imitate yours	17 minutes	19 minutes
7	ABC's of behaviour	Understanding why behaviour happens and how your child learns	20 minutes	23 minutes
8	Joint attention triangle	How to show your child to give, show and share interest	23 minutes	24 minutes
9	Play, pretend, and communicate	Why these are so important	26 minutes	24 minutes
10	Putting it all together	How to incorporate everything you learnt in everyday interactions	17 minutes	17 minutes
Total			208 minutes	217 minutes

Supplementary materials were also created to be provided to parents after each module, to solidify their learning. This was in the form of a written post that included a recap of the objectives of the module, as well as a checklist of points to reflect on while practicing the strategies covered (Figure 2.6). All supplementary materials will be available to access in a 'Thesis Supplementary Folder' located on a Microsoft Teams shared drive.

Figure 2.6

Example of checklist provided as supplementary material for module 7 (ABC's of Behaviour).



This week, our aim was to: **1) To use the ABC's to understand and teach new behaviors**

Think about ….

- ☐ **Everything your child does has a reason! Can you identify what is their goal?**
- ☐ **What happens after your child's behavior is what solidifies it. Be aware of what rewards you are providing after a behavior, and is that what you want to reward?**
- ☐ **What do you want them to do instead? replace unwanted behaviors with acceptable ones.**
- ☐ **Are the replacement behaviors you are teaching your child as easy, efficient and effective as the original behavior?**
- ☐ **The reward is what makes the behavior stick! Are you reinforcing the replacement behaviors?**

Evaluation of Intervention and Adaptation of Contextually Fit Outcome Measures

An integral part of planning the process and provisions of implementing an intervention in a specific setting, is considering the culturally and contextual validity of the outcome tools used to measure the effectiveness of the intervention. There are some relevant screening tools that have been translated into Arabic and validated in this population, such as the Arabic M-CHAT-R (Eldin et al., 2008). However, there are limited Arabic outcome tools that can be used to measure implementation, fidelity, or intervention outcomes valid for NDBIs and ASD research.

To understand the impact of the intervention on parent stress, family experience, parent knowledge, and child social communication, the below tools were chosen to utilise in different stages of our research program:

a) Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2014)
b) Autism Family Experience Questionnaire (AFEQ) (Leadbitter et al., 2018)
c) Social Communication Checklist-Revised (SCC-R) (Weiner et al., 2017)
d) Autism Parenting Stress Index (APSI) (Silva & Schalock, 2011)
e) Treatment Acceptability Rating Form (TARF) (Reimers & Wacker, 1988)
f) Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), and Feasibility of Intervention Measure (FIM) (Weiner et al., 2017)
g) Behaviour Vignette
h) Attitude and Engagement in Intervention Questionnaire (AEIQ)

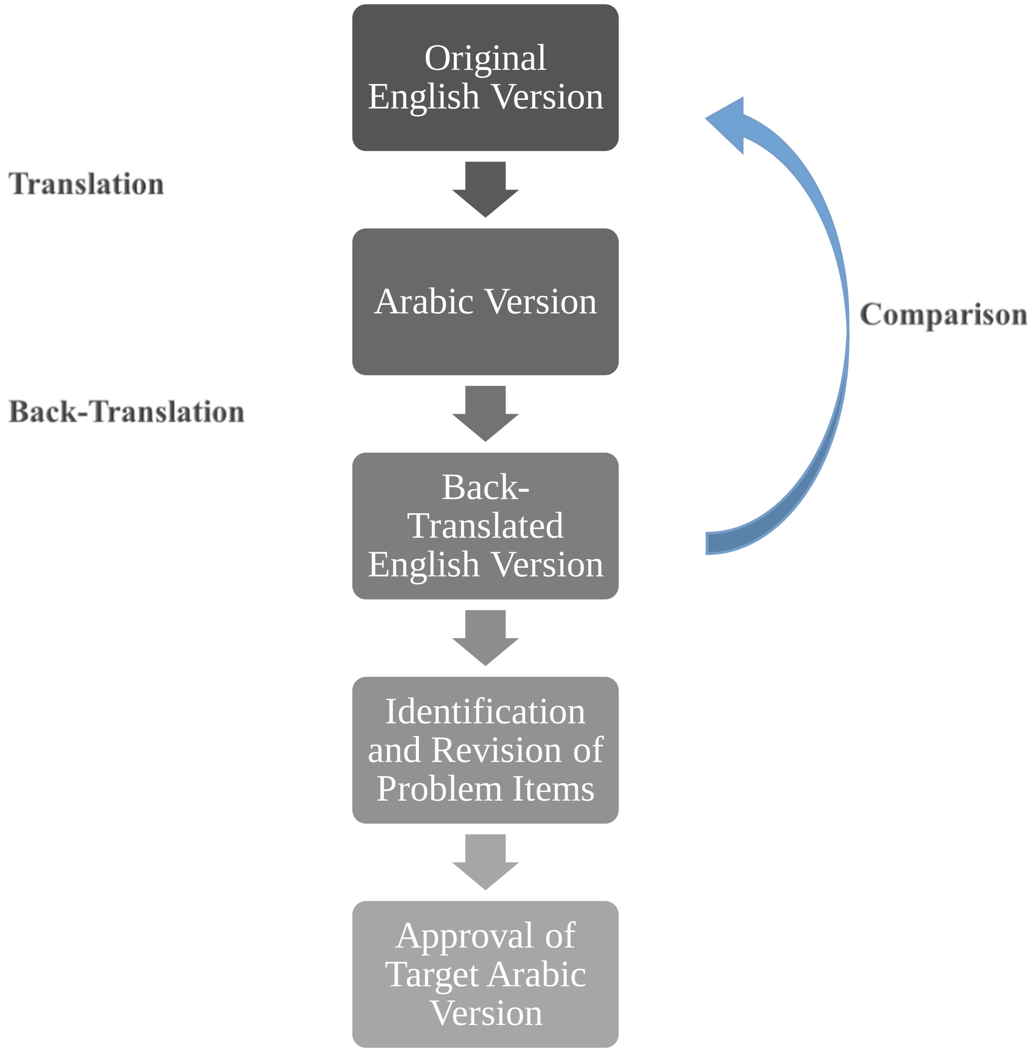
To enhance the quality and validity of research, it is important to consider rigorous methods in the translation and validation of instruments and outcome tools, such as back-translation, especially in cross-cultural research (Sperber, 2003). This often involves a multi-stepped approach that includes: involvement of original author in translation process and obtaining approval; forward translation of items from source language to another language; back-translation into source language and analysis of items; review and revision of forward translation; and final approval of target version (Acquadro et al., 2008).

The primary investigator, who is bilingual and fluent in both English and Arabic, underwent the process of formally translating the AFEQ, SCC-R, as they were not available in Arabic at the time of research. This process involved back-translation, whereby each item within the tool was translated into Arabic, after which an independent translator carried out back-translation from Arabic to English. The independent translator, who was a bilingual Speech and Language Pathologist working at AJCH at the time, had not accessed the original English version of the tool to avoid any bias. The back-translated version was then reviewed for any discrepancies in meaning prior to receiving final approval. (see Figure 2.7).

In regard to other tools used, the items were either directly interpreted and translated during direct face-to-face interviews with participants, such as the case for APSI and TARF and AIM/IAM/FIM, or they were created in Arabic by the primary investigator since they were developed exclusively for the research program, such as for the Behaviour Vignette and the AEIQ. All translated tools and developed outcome measures will be available to access in a ‘ Thesis Supplementary Folder ’ located on Microsoft Teams.

Figure 2.7

Flow diagram of the multi-step approach utilised in translation and validation of the AFEQ, SCC-R and AIM/IAM/FIM.



Autism Family Experience Questionnaire (AFEQ)

Permission to utilise the AFEQ in our research program and undergo translation was received in October 2021, by the lead author of the questionnaire, Dr Kathy Leadbitter, through e-mail communication. The primary investigator completed process of back-translation, which included a request by Dr Leadbitter to revise some of the translated items due to a drift in the meaning between the back-translated version and the original version. Final approval of Arabic version was received in October 2021 by Dr Leadbitter. Table 2.4 below presents the items from the original English version of the AFEQ and the back-translated English version.

Table 2.4

Comparison of the 48 items from the original English version of the AFEQ and the back-translated English version.

Item	**Original English Version**	**Back-Translated English version**
1	I lack confidence in knowing how to help my child.	I lack the confidence to know how to help my child.
2	I feel listened to by professionals.	I feel that professionals listen to me
3	Working with therapists or professionals helps me feel confident.	Working with professionals helps me feel confident
4	I am confident that I understand my child’s level of development.	I am confident that I understand my child’s development level
5	I feel I know how to help my child progress.	I feel that I understand how to help my child progress.
6	I feel I’m getting it wrong.	I feel that I am doing things in the wrong way
7	I have realistic milestones for my child’s development.	I have realistic milestones for my child’s development.
8	I doubt my ability to help my child’s development.	I doubt my ability to help my child develop.
9	I feel frustrated at not knowing how to help my child	I feel frustrated about not knowing how to help my child develop.
10	I have coping mechanisms to help my child.	I have coping strategies to help my child.
11	Professionals don’t understand my family’s needs.	Professionals do not understand my family’s needs.
12	It’s a continual battle to get the right help for my child.	It is a constant battle to get appropriate help for my child.
13	My child is getting the right help.	My child gets the right support.

14	Family life is a battle.	Family life is a battle.
15	I feel guilty about not giving other members of the family enough attention.	I feel guilty for not giving other family members enough attention.
16	My child is flexible in adapting to the demands of family life.	My child is flexible in adapting to the demands of my family life.
17	Family life is calm.	Family life is calm.
18	I know how to cope with my child when going on an outing in a public place e.g., café or restaurant.	I know how to manage my child when going on an outing in public (e.g., café or restaurant)
19	I feel confident to go out to family events with my child	I feel confident going to family events with my child.
20	I feel confident in making routines at home more manageable for my child	I feel confident in knowing how to make our daily routine easier on my child.
21	I feel comfortable about having visitors to our home	I feel comfortable receiving guests at home.
22	My child has fussy eating that makes it difficult to go away for a break	My child struggles with picky eating which makes it difficult to go on trips.
23	My child can concentrate on an activity for a short time	My child is able to focus on an activity for a short period of time.
24	My child can spontaneously begin communication with me	My child is able to spontaneously initiate communication with me.
25	My child spontaneously begins communication with other members of the family	My child spontaneously initiates communication with other family members.

26	My child can request his/ her needs appropriately	My child is able to appropriately request for his needs.
27	My child gets frustrated at not being understood	My child gets frustrated when he is not understood.
28	My child can let me know when he/ she is hurt	My child is able to let me know when he is hurt.
29	I know when my child feels poorly	I know when my child is feeling unwell or sick.
30	My child has repetitive behaviour and sensory interests that make it difficult to go on an outing	My child has repetitive behaviours and sensory interests that make it difficult for him to go on outings.
31	My child is good at sharing with others	My child is good at sharing with others.
32	My child has to have his/ her own way	My child gets his own way.
33	My child is aware of other people’s needs	My child is aware of the needs of others.
34	My child gets invited to birthday parties	My child is invited to birthday parties.
35	My child plays with other children	My child plays with other children.
36	I have to go with my child to supervise play with other children	I have to go with my child to supervise play with other children.
37	My child is happy	My child is happy.
38	My child is anxious	My child is anxious.
39	My child is tolerant of mistakes	My child is tolerant of others’ mistakes.
40	My child is calm	My child is calm.
41	My child in angry	My child is angry.

42	My child is unpredictable.	My child is unpredictable.
43	My child can let me know what he/she is upset about	My child is able to communicate what he's upset about.
44	My child understands appropriate behaviour in familiar social situations	My child understands appropriate behaviour in familiar social settings.
45	My child knows the difference between family members and strangers	My child understands the difference between family members and strangers.
46	My child acts differently with family members compared with strangers	My child acts differently with family members than strangers
47	My child is embarrassing when going out	My child is embarrassing during outings.
48	My child has repetitive behaviours that make day to day life impossible	My child has repetitive behaviours that make daily life impossible.

Social Communication Checklist-Revised (SCC-R)

Permission to utilise the SCC-R in our research program and undergo translation was received in October 2021, by the lead author of the questionnaire, Dr Allison Weiner, through e-mail communication. The primary investigator completed the formal process of translation, which includes initial and back-translation, and final approval for the use of the Arabic version was received on the 13th of October 2021 by Dr Weiner. Table 2.5 below presents the items from the original English version of the AFEQ and the back-translated English version.

Table 2.5

Comparison of the 69 items from the original English version of the SCC-R and the back-translated English version.

Item	Original English Version	Back-Translated English version
1	Does your child enjoy face-to-face interaction with you?	Does your child enjoy interacting with you face-to-face?
2	Does your child prefer to be near you or other family members?	Does your child prefer to be near you or another family member?
3	Does your child maintain simple social games for at least 3 turns (e.g., peek-a-boo, chase)?	Does your child continue to play simple social games for at least 3 turns (e.g., peek-a-boo, chase)?
4	Does your child remain actively engaged with you during social games for at least 5 minutes?	Does your child remain actively engaged with you during social games for at least 5 minutes?
5	Does your child remain actively engaged with you during social games for at least 10 minutes?	Does your child remain actively engaged with you during social games for at least 10 minutes?
6	Does your child remain actively engaged with you during toy play for at least 2 minutes?	Does your child remain actively engaged with you during toy play for at least 2 minutes?
7	Does your child remain actively engaged with you during toy play for at least 5 minutes?	Does your child remain actively engaged with you during toy play for at least 5 minutes?
8	Does your child remain actively engaged with you during toy play for at least 10 minutes?	Does your child remain actively engaged with you during toy play for at least 10 minutes?
9	Does your child lead play or try to continue with play once you have stopped (e.g., make eye contact, smile at you, vocalize, or touch you)?	Does your child lead play or continue to play when you stop (e.g., making eye contact with you, vocalise, smile at you, or touch you)?

10	Does your child respond to your attempts to draw his/her attention to something or someone (when you use a point, language, or shift your gaze)?	Does your child respond to your attempts to direct his/her attention to someone or something (e.g., when you point, use language, or shift your eye gaze)?
11	Does your child make eye contact while interacting or communicating with you?	Does your child make eye contact while interacting or communicating with you?
12	Does your child initiate activities or play with you (e.g., offer you a toy or find you to come play with him)?	Does your child initiate an activity or play with you (e.g., present a toy to you, or look for you to play with them)?
13	Does your child take turns with you?	Does your child take turns with you?
14	Does your child point or show you objects that interest him/her for the purposes of sharing?	Does your child point out or show objects of interest to share with you?
15	Does your child provide greetings and farewells when people come into or leave the room?	Does your child greet people entering or leaving a room?
16	Does your child babble, or use speech-like sounds?	Does your child babble or make sounds that resemble speech?
17	Does your child use gestures to request items or actions (e.g., lead you to an object, point, sign)?	Does your child use gesture to request for objects or actions (e.g., lead you to something, point with figure, use sign language)?
18	Does your child communicate a clear choice when presented with 2 alternatives (e.g., by reaching, using eye gaze, using sounds or words)?	Does your child communicate a clear choice when presented with two options (e.g., reach for, make eye contact, use a vocalization or word)?
19	Does your child imitate your speech sounds or language?	Does your child imitate your sounds or language?
20	Does your child use single words spontaneously?	Does your child use single words spontaneously?
21	Does your child name objects?	Does your child name objects?

22	Does your child name actions?	Does your child name actions?
23	Does your child combine words into simple phrases (e.g., “Go car” “Push train”)?	Does your child combine words to make simple phrases (e.g. ‘go car’ or ‘push train’)?
24	Does your child use words to describe objects (e.g., “Big red ball” “Little, green ball”)	Does your child use words to describe objects (e.g. ‘big red ball’ ‘small green ball’)?
25	Does your child use pronouns appropriately?	Does your child use pronouns appropriately?
26	Does your child use a variety of tenses (words with “ing” or “ed” endings)?	Does your child use a variety of tenses (e.g. eat-ing in present tense, play-ed past tense)?
27	Does your child consistently use sentences to communicate?	Does your child consistently use sentences to communicate?
28	Does your child answer simple questions about himself (e.g., “What is your name?” “How old are you?”)?	Does your child answer simple questions about themselves (e.g., ‘what’s your name’, or ‘how old are you’)?
29	Does your child answer simple questions about his wants, needs, or environment? (e.g., “What do you want?” “What is it?” “Where is it?”). If yes please circle the type of question they answer.	Does your child answer simple questions about their wants and needs or their environment (e.g. ‘what do you want’ ‘what is’, or ‘where is’)? If you answered yes, please indicate what type of question do they answer.
30	Does your child answer who, why, or how questions? (e.g., “Who is driving the car?” “Why are you sad?”) If yes, please circle the type of questions he answers.	Does your child answer ‘who’ ‘why’ or ‘how’ questions (e.g., ‘who’s driving the car’, ‘why are you sad’)? If you answered yes, please indicate what type of questions do they answer.
31	Does your child babble or use speech-like sounds in a way that is intentionally directed at you (to communicate)?	Does your child babble or use speech-like sounds in a way that is directed at you (to communicate)?

32	Does your child use gestures, eye contact, sounds, or language to request desired items or activities? (Indicate *nonverbal* or *verbal* strategies)	Does your child use gestures or eye contact or sounds or language to request for items or activities they want? Indicate if ‘verbal’ or ‘non-verbal’
33	Does your child use gestures, facial expressions, sounds, or language to protest or tell you he does not want something? (Indicate *nonverbal* or *verbal* strategies)	Does your child use gestures or facial expressions or sounds or language to refuse or tell you they don’t want something? Indicate if ‘verbal’ or ‘non-verbal’.
34	Does your child use gestures, sounds, or language to ask for help? (Indicate *nonverbal* or *verbal* strategies)	Does your child use gestures or sounds or language to request for help? Indicate if ‘verbal’ or ‘non-verbal’.
35	Does your child use gestures or language to share information (e.g., “I see a plane”)? (Indicate *nonverbal* or *verbal* strategies)	Does your child use gestures or language to share information (e.g. ‘I see a plane’)? Indicate if ‘verbal’ or ‘non-verbal’.
36	Does your child use gestures or language to gain your attention (e.g., “Mom, come here”)? (Indicate *nonverbal* or *verbal* strategies).	Does your child use gestures or language to get your attention (e.g. ‘mom, come here’)? Indicate if ‘verbal’ or ‘non-verbal’.
37	Does your child use words to tell you how he is feeling (e.g., “hurt” “mad” “happy”)? (Indicate *nonverbal* or *verbal* strategies).	Does your child use words to tell you how they feel (e.g. ‘hurt’ ‘upset’ ‘happy’)?
38	Does your child use words to tell you what to do (e.g., “Feed the baby” “Push the car”)?	Does your child use words to tell you what you need to do (e.g. ‘feed the baby’, ‘push the car’)?
39	Does your child tell you about events that have already occurred?	Does your child tell you about events that have occurred?
40	Does your child use words to tell you a simple story?	Does your child use words to tell you a simple story?

41	Does your child ask you questions for information (e.g., “What is that?” “Where is dog?” “Why?”)? If yes, please indicate the type of questions.	Does your child ask questions to get information (e.g., ‘what’s this’ ‘where’s the dog’ ‘why’)? If the answer is yes, please indicate what type of question they ask.
42	Does your child ask who, why, or how questions? If yes, please circle the type of questions they ask.	Does your child ask ‘who’ ‘why’ and ‘how’ questions? If yes, please indicate what type of question they ask.
43	Does your child participate in a conversation that is initiated by an adult for 3 consecutive turns?	Does your child participate in conversation that an adult initiates for at least 3 consecutive turns?
44	Does your child participate in a conversation that is initiated by an adult for more than 3 consecutive turns?	Does your child participate in conversations that an adult initiates for more than 3 turns?
45	Does your child initiate conversations with others?	Does your child initiate conversations with others?
46	Does your child consistently look when his name is called?	Does your child consistently look when you call their name?
47	Does your child look to people/photos of people when named?	Does your child look at others/picture of others when they are named?
48	Does your child respond by stopping actions in response to inhibitory words (e.g., “no”, “stop’)?	Does your child stop in response to an inhibitory word (e.g., ‘no’ or ‘stop’)?
49	Does your child identify several named body parts?	Does your child identify several parts of the body when named?
50	Does your child respond appropriately to one step directions in natural play, dressing, or eating routines?	Does your child respond appropriately to 1-step directions during natural play or getting dressed or eating routine?
51	Does your child follow directions with more than one step in natural play, dressing, or eating routines?	Does your child follow multi-step directions during natural play or getting dressed or eating routine?
52	Does your child retrieve several requested objects that are in the room but not directly in in front of him?	Does your child retrieve several requested items that are in the room but not directly in front of them?

53	Does your child complete a task and then put away the play materials?	Does your child complete a task and put material away?
54	Does your child imitate facial expressions or movements (e.g., tongue thrust)?	Does your child imitate facial expressions or movements (e.g., sticking tongue out)?
55	Does your child imitate actions or body movements within songs or known routines (e.g., wheels on the bus movements)?	Does your child imitate actions or body movements during songs or familiar routines (e.g., rolling hands during ‘wheels on the bus’)?
56	Does your child imitate conventional gestures (e.g., wave bye-bye, blow kisses, clap hands, etc.)?	Does your child imitate common gestures (e.g., wave ‘bye’, flying kiss, clap hands etc.)?
57	Does your child imitate familiar play actions (actions that your child does on his or her own) after seeing you do them?	Does your child imitate familiar actions in play (actions that your child does on their own) after seeing you do them?
58	Does your child imitate novel play actions (actions that your child does not do on his or her own) after seeing you do them?	Does your child imitate new play actions (actions that your child does not do on their own) after seeing you do them?
59	Does your child engage in longer imitative interactions with you during play in which you take turns imitating each other?	Does your child engage in prolonged imitative play with you where you take turns in imitating each other?
60	Does your child use toys in an exploratory manner (e.g., touching, mouthing, smelling, looking)?	Does your child use toys in an explorative way (e.g. touch, taste, smell, look)?
61	Does your child combine objects together (e.g., nesting one object in another, putting objects in containers, lining, stacking, ordering toys in certain ways)?	Does your child combine things together (e.g., putting an object inside another, putting things in a container, lining up, arrange toys in a specific order?

62	Does your child use cause and effect toys (e.g., mechanical toys, pop-up toys)?	Does your child use cause-and-effect toys (e.g., mechanical toys)?
63	Does your child use toys for their intended purpose (e.g., throw a ball, push a car)?	Does your child use toys for their intended purpose (e.g. throw a ball, push a car)?
64	Does your child direct familiar pretend play actions towards him/herself (e.g., pretend to eat, pretend to sleep, pretend to talk on a toy phone)?	Does your child direct pretend play actions towards himself (e.g., pretend to eat food, pretend to sleep, pretend to talk on phone)?
65	Does your child direct basic pretend play towards another person or a doll or other toy (e.g., pretend to feed a parent or a baby doll, dress a doll, put a doll to bed)?	Does your child direct basic pretend play towards another person or doll/toy (e.g., pretend to feed parent/doll, dress up a doll, putting doll in bed)?
66	Does your child pretend that one thing represents another (e.g., pretend a block is a car or a stack of blocks is a building), attribute characteristics to an object that it does not have (e.g., pretend that toy food is "hot" or tastes "yummy"), or animate objects (e.g., make a figurine walk or have a doll hold a cup rather than placing a cup to the doll's mouth)?	Does your child pretend that an object represents something else (e.g., pretend a block is a car, or a group of blocks is a building), attribute a characteristic to an object that does it doesn't have (e.g., pretend that play food is hot or tasty), or an animate being (e.g. make the doll grasp a cup instead of placing cup on doll's mouth)?
67	Does your child link several pretend actions together or tell an extended story with toys (e.g., put doll in car and push car to store)?	Does your child combine several pretend play actions together or tell a long story with toys (e.g., put a doll in the car and push the car to the store)?
68	Does your child take on an imaginary role (e.g., pretend to be a doctor, fireman, mommy/daddy) during play?	Does your child role play (e.g., pretend to be a doctor or fireman or a mother/father) during play?
69	Does your child tell an extended story while taking on an imaginary role with at least one other person (e.g., child is doctor, parent is patient; child is mommy, sibling is baby)?	Does your child tell a long story while role-playing with at least one other person (e.g., child is a doctor and father is sick, or child is a mother, and the younger brother is the baby)?

Adapting evidence-base interventions in a way that allows implementation in a culturally and linguistically diverse population, such as the case in the UAE, may enhance the likelihood of improving access to intervention for young children with ASD and their families. Further, translation and validation of outcome measures into Arabic can facilitate a better understanding of the impact of intervention within the population of the UAE and surrounding Arab countries, as well as improve the quality and validity of research. Importantly, this also makes a contribution to expanding research scope to geographic locations by ensuring measured outcomes are similarly recorded to those where such measures originated. There have been calls to standardise outcome measures (Lord et al., 2021) in autism intervention studies and facilitating translation of frequently employed valid instruments adds to the external validity of any findings related to intervention outcomes.

Chapter 3

Tele-Coaching Parents of Toddlers' 'at Risk' of Autism in the United Arab Emirates using Naturalistic Developmental Behavioural Interventions (NDBI): A Pilot Study

In the UAE, positive steps have been taken towards improving the quality of life of children with ASD and their families; however, there continues to be a service-need gap with long wait times to receive ASD diagnostic assessments; few early intervention services for ‘at risk’ toddlers in urban and remote areas of the UAE; and limited funding of evidence-based interventions for ASD from government or private insurance companies.

In Chapter 1, the rationale for utilising telehealth to deliver parent-mediated Naturalistic Developmental Behavioural Interventions (NDBI) in order to facilitate immediate access to effective early intervention was described. From this, it is clear that tele coaching parents on how to utilise learning opportunities in natural everyday activities may enhance their child’s social emotional development. Chapter 2 described the procedures for developing an intervention program that utilises a hybrid approach to telehealth delivery, including asynchronous online video modules and synchronous tele-coaching sessions. Specifically, the focus was on the adaptation of specific outcome measures into the Arabic language to allow for the collection of relevant data from all participants, as well as the contextual fit of the intervention program being implemented in the UAE based on a brief experience of a pilot trial during the COVID-19 pandemic, whereby a group of four parents participated in a four-week cycle of intervention delivered twice weekly via synchronous tele-coaching sessions. Outcomes from the trial informed the development of the intervention program investigated.

Implementation science research emphasises that it is important to consider dissemination and implementation of effective intervention, the local context and setting, the local caregivers, and pragmatic evaluations, in order to achieve sustainable and scalable services (Schlebusch et al., 2020). The majority of parent mediated NDBIs have been developed in high-income countries and are researched within what may be considered a non-representative population with <3% of participants coming from Africa, South America, Asia, or the Middle East (Nielsen et al., 2017). Therefore, when implementing NDBIs in low-resource settings, it is important to consider the cultural context of where the intervention will occur, which developmental and behavioural goals to target, and how to measure effectiveness of intervention in the absence of contextually valid tools (Schlebusch et al., 2020).

Further, in resource limited settings, considering a group-based format for delivery of training in effective intervention may reduce the 'cost' per session on parents, as well as facilitate social support for parents in a more natural way (Stuttard, et al., 2016). Indeed, group-based intervention delivered to parents of children with autism may improve their knowledge and understanding of ASD through access to information and shared experiences, as well as improved parent self-efficacy (O'Donovan et al. 2019). Parents from the Pilot study conducted at Al Jalila Children's Hospital during the Covid-19 pandemic also described their feelings of being supported and less isolated during their experience being in a group-based intervention. Therefore, it is useful to investigate this modality of delivery in the context of the UAE.

The current chapter provides an examination of individual and group-based coaching of parent-mediated NDBIs delivered through telehealth to parents of toddlers at risk of ASD with limited access to early intervention services in the UAE, including: a) initial feasibility and acceptability; b) effect of modality of delivery on parent knowledge and engagement; c) the impact on parent reported improvement in social emotional behaviours, as the first stage of this research program.

Method

Setting and Participants

The current study was conducted in 2021 and 2022 at Al Jalila Children's Specialty Hospital, a dedicated paediatric hospital located in the emirate of Dubai, United Arab Emirates. The hospital is a public hospital comprised of five centres of excellence that provide a range of specialty clinics, including paediatric mental health, which offers a dedicated program for autism spectrum disorder. The Autism program offers comprehensive diagnostic evaluations conducted by a multi-disciplinary team of Psychiatrists, Neurodevelopmental Paediatricians, Psychologists, Behaviour Analysts, and Speech and Language Pathologists.

Ethical approval was obtained by both Trinity College Dublin, School of Psychology and Dubai Healthcare City Research Ethics Committee – endorsed by Al Jalila Children's Hospital research council. The primary investigator held a Masters degree in Autism Studies and was a bilingual (English/Arabic) licensed behaviour analyst working in Dubai Healthcare City since 2015 with training in the Early Start Denver Model to an advanced level.

The Al Jalila Children's Specialty Hospital waitlist of children 'under 4 years' awaiting diagnostic evaluation was scanned for participants. Parents were contacted by phone and invited to participate if : a) they had a child between 18-36 months, identified as 'at risk' of ASD, scoring as positive during screening with M-CHAT (total score > 7); b) they were residents of urban and non-urban areas with no access to licensed ABA service providers; c) same parent was available to attend training during the 10-week intervention period; d) they had a camera enabled electronic device with home access to an internet connection; e) were English and/or Arabic speaking. Out of 52 parents that met inclusion criteria, 26 parents were interested in participating and were sent the information sheets, recruitment letters, and consent forms by e-mail, after which 19 parents signed consent to participate in the study. During the intervention phase of the study, five parents withdrew their participation and a total of 14 participants completed the study.

All 14 participants in both control and intervention groups were mothers who were married. The majority of participants in both control and intervention groups were between the ages of 30-39 years old, residing in the emirate of Dubai, and had 2 or more children, and were un-employed. Education level of participants in the intervention group were higher than the control group. Table 3.1 below summarises the demographic data of all participants.

Table 3.1.

Summary of participant demographic data from Control group, Individual -Coaching Parent Mediated Intervention (I-CPMI) and Group-Coaching Parent Mediated Intervention (G-CPMI).

Characteristics	Control (%)	I-CPMI (%)	G-CPMI (%)
Gender			
Male	0 (0)	0 (0)	0 (0)
Female	7 (100)	2 (100)	5 (100)
Age			
20-29 years	3 (43)	0 (0)	0 (0)
30-39 years	4 (57)	1 (50)	5 (100)
40-49 years	0 (0)	1 (50)	0 (0)
Nationality			
Emirati	1 (14)	0 (0)	2 (40)
Arab	3 (43)	1 (50)	3 (60)
Other	3 (43)	1 (50)	0 (0)
Emirate of Residence			
Dubai	6 (86)	1 (50)	4 (80)
Other Emirate	1 (14)	1 (50)	1 (20)
Education level			
High School	3 (43)	0 (0)	1 (20)
College	1 (14)	0 (0)	0 (0)
Undergraduate	3 (43)	1 (50)	4 (80)
Graduate	0 (0)	1 (50)	0 (0)
Number of Children			
1	1 (14)	0 (0)	0 (0)
2	5 (72)	1 (50)	1 (20)
3	0 (0)	0 (0)	2 (40)
>3	1 (14)	1 (50)	2 (40)
Employment			
Full-Time	1 (14)	1 (50)	1 (20)
Un-employed	6 (86)	1 (50)	4 (80)
Preferred Language			
Arabic	5 (72)	1 (50)	3 (60)
English	2 (28)	1 (50)	2 (40)

Design

The current study adopted a randomised three group experimental design with pre/post-test. Consenting participants (n=19) completed baseline outcome measures and questionnaires (T1). To maintain balance in treatment groups, participants were then randomly assigned into one of three groups using an online random number generator: a) Psychoeducation (PE) only group (n=7); b) Individual – Coaching Parent Mediated

Intervention (I-CPMI) (n=6); or c) Group – Coaching Parent Mediated Intervention (G-CPMI) (n=6).

Measures

Pre-intervention measures (T1): All pre-intervention baseline measures were completed by parent participants with the support of the primary investigator. Three participants completed the baseline measures by physically attending the hospital, however, due to changes in hospital regulations and new restrictions following a spike in COVID-19 cases at the time in the UAE, the remaining participants completed the measures over the phone. Outcome measures were provided in both English and Arabic based on Parent's preferred language.

a) Demographic Questionnaire: A 9 item bilingual questionnaire was developed by the primary investigator to collect participant demographics including their gender, age, relationship status, nationality, place of residence, education status, number and age of children, employment status.

b) Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2014): The M-CHAT is a parent completed screening tool used to identify behaviours associated with ASD. Internal consistency is adequate (Cronbach's alpha 0.79). The M-CHAT was used as a pre-intervention measure to identify children 'at-risk' and as a baseline measure for comparison post-intervention. The Arabic translation of the M-CHAT is available and has been previously validated (Eldin et al., 2008).

c) Autism Parenting Stress Index (APSI) (Silva & Schalock, 2011): This is a measure of parenting stress specific to core ASD behaviours (social development, communication, feeling close to child, Acceptance by others, and Future independence) and co-occurring features of autism (Challenging behaviours, Sleep, Diet, and Toileting). The overall APSI scale score demonstrates acceptable internal consistency (Cronbach’s alpha 0.83) and test-retest stability (Cronbach’s alpha 0.88) for parents of children with autism. Psychometric properties are good (e.g., Cronbach's alpha 0.83).

d) Autism Family Experience Questionnaire (AFEQ) (Leadbitter et al., 2018): The Autism Family Experience Questionnaire (AFEQ) measures broader impact of an intervention on the family, including experience being a parent (Cronbach’s alpha 0.85), family life (0.83), child development (0.81), child symptoms (0.79), with an AFEQ total score (0.92). Permission to use the AFEQ and approval of Arabic back translation was received by its lead author (Dr. Kathy Leadbitter) in October 2021.

e) Social Communication Checklist-Revised (SCC-R) (Weiner et al., 2017): SCC-R is a 70-item checklist completed by parents to indicate if their child uses skills related to social engagement, expressive and receptive communication, and imitation/play. Internal consistency and test-re-test reliability were found to be good to excellent (Cronbach’s alpha 0.985 for total score, Interclass correlation 0.855). Permission to use the SCC-R and approval of Arabic back translation was received by its lead author (Dr. Allison Weiner) in October 2021.

f) Behaviour Vignette (Arnold et al., 2003): The protocol was developed by the Research Units on Paediatric Psychopharmacology Autism Network and has demonstrated high levels of agreement between expert raters with Intraclass Correlation Coefficient of 0.895 across a panel of five raters (Arnold et al., 2003). A Behaviour Vignette relevant to the content of the intervention was created in both Arabic and English and used as a measure of acquired knowledge. Participants were presented with four different scenarios and undertook a detailed semi-structured interview during which they identified problem behaviours and potential functions.

Post-Intervention Measures (T2): All post-intervention measures were completed by participants on the phone following the completion of the 10-week intervention cycle. In addition to the measures completed at T1 (M-CHAT, APSI, AFEQ, SCC-R, Behaviour Vignette) the below measure was completed:

a) Treatment Acceptability Rating Form (TARF) – (Reimers & Wacker, 1988): The TARF is a 15-point scale that measures parents' acceptability of treatments devised within a clinical setting and the social validity of the recommended intervention. The TARF measures sub-domains related to intervention 'Reasonableness', 'Effectiveness', 'Willingness', 'Total cost', 'Side-Effects', and 'Disruptiveness'.

Procedure

At the start of the 10-week intervention program, all participants received a 'welcome e-mail' with a brief outline of the program and instructions on accessing the video modules. Learning modules were pre-recorded by the primary investigator and include themes based on the Early Start Denver Model parent manual (Rogers & Dawson, 2012), including: joint attention; imitation; reciprocal interaction; verbal and non-verbal communication; 'behaviour' and play (see Figure 3.1).

Figure 3.1.

Outline of weekly theme targeted in pre-recorded video modules.

Week	1	2	3	4	5
	Introduction to program **'Setting the scene'** at home	**Stepping into your child's Spotlight** Increasing attention to you, to increase their opportunities to learn	**Finding the Fun** Increasing smiles and laughing during sensory social routines.	**Building back-and-forth interactions** Building joint interaction routines into daily activities	**Talking Bodies** using non-verbal communication and understanding others' body language to express interests and feelings
Week	**6**	**7**	**8**	**9**	**10**
	"Do what I Do!" Imitating your child's sounds, gestures, facial expressions, actions, and words to teach your child to imitate yours.	**ABC's of Behavior** Understanding why behavior happens and how your child learns	**Joint Attention** How to teach your child to give, show, and share interest	**Play, Pretend, and Communicate** Why these are so important	**Putting it all together**

Participants assigned to the I- CPMI group received planned intervention, consisting of access to online learning modules, in addition to weekly individual tele-parent coaching sessions conducted by the primary investigator via Microsoft Teams. At the beginning of each week, participants were given access to the online learning module specific to the week's learning objective and were instructed to complete the module by watching the pre-recorded video presentation and completing the task assigned for that week as pre-requisite learning prior to attending the scheduled parent coaching session for that week. Weekly parent coaching sessions (1.5 hours/session) were structured while being collaborative and included opportunities for parents to reflect on progress and/or challenges during the past week, coaching of a new theme for the upcoming week, and an opportunity at the end to discuss any questions or concerns.

Participants assigned to the G-CPMI also received planned intervention, consisting of access to online learning modules, which they completed individually, in addition to weekly group based tele-parent coaching sessions. There were two G-CPMI cohorts consisting of three parent participants randomly assigned to each cohort. Weekly group based coaching sessions were structured similarly to the I-CPMI group, however, given the nature of the group-based sessions, parents also had an added opportunity to learn through sharing of questions, examples, and experiences in implementing the strategies with coaching provided. In an effort to balance group dynamics with the need for focused/personalised attention and informed by parents' experiences from our pilot trial during the COVID-19 pandemic (described in Chapter 2), the small group-based sessions were capped to three parent participants. This was observed to facilitate better alignment between the intervention and the individual needs of each family within their unique ecological environment, fostering opportunities for meaningful interactions and exchange of ideas.

Participants assigned to the PE control group received weekly access to the online modules only (no tele-parent coaching sessions) to complete at their own pace over the 10-week cycle.

At week 5, there was a one-week break from intervention. Participants were provided with written overview material from the content covered in the first five weeks to review. Following the 10-week cycle of intervention (T2), participants completed post-intervention outcome measures and questionnaires.

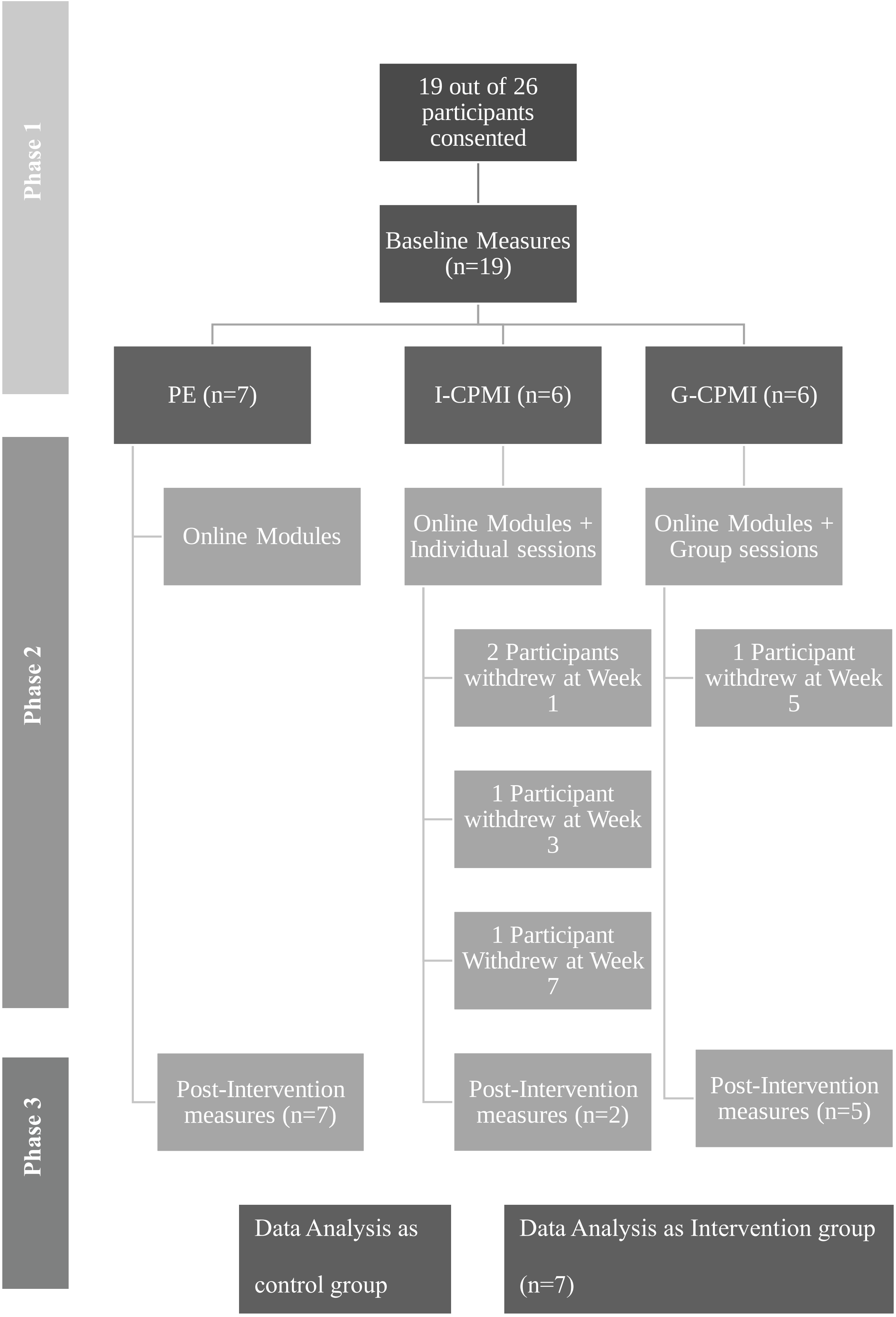
A total of 14 participants completed the study and all post-intervention outcome measures. Participants withdrew from the I-CPMI (n=4) and G-CPMI (n=1) between weeks 1-7, with majority (n=4) withdrawing at week 5 or earlier. Participant that withdrew cited 'having no time to commit to the sessions' (n=3) or 'ill with COVID-19' (n=3) as their reason for being unable to continue (see Figure 3.2).

Data Analysis

Pre and post intervention data from participants in both I-CPMI and G-CPMI groups were presented together as the intervention group for ease of visual analysis. Outcomes from the behaviour vignette measure of acquired knowledge were analysed by first scoring each task from each of the four given scenarios A score of ‘1’ was given for each response that was an example of ‘Identifying Un-desired Behaviour’, ‘Identifying Environmental Factors’ contributing to behaviour, ‘Proposing Alternative Behaviour’, and ‘Proposing Modification to the Environment’ within each of the four scenarios. A score of ‘0’ was given for the absence of response. The scores were tallied for each participant (with a maximum attainable total score of 16) and percentage was calculated for comparison of data.

Figure 3.2.

Outline of the three phases of the study.



Results

Attendance

Data on the attendance of participants in the intervention group were collected. While the two participants in the I-CPMI attended all 10 sessions, only 2 out of the 5 parents from the G-CPMI demonstrated 100% attendance, both whom belonged to the same group cohort (Table 3.2). The other 3 participants from the G-CPMI did not attend all sessions due to reasons related to “illness” or being “busy” on the date of their scheduled session.

Table 3.2.

Attendance of participants in the I-CPMI and G-CPMI for scheduled coaching sessions during the 10-week intervention.

Participant	**Week**										**Total attendance (%)**
	1	***2***	***3***	***4***	***5***	***6***	***7***	***8***	***9***	***10***	
I-1	+	+	+	+	+	+	+	+	+	+	100%
I-2	+	+	+	+	+	+	+	+	+	+	100%
G-1	+	+	+	+	+	+	+	+	+	+	100%
G-2	+	+	+	+	+	+	+	+	+	+	100%
G-3	+	-	+	+	+	+	+	-	+	-	70%
G-4	+	+	+	-	-	+	-	+	+	-	60%
G-5	+	+	+	+	+	-	+	+	+	-	80%

Identification of Behaviours Associated with Autism

Comparison of M-CHAT scores in Intervention group showed an overall decrease in the total scores in 5 out of 7 participants post-intervention with an average percentage change of 20% (see Figure 3.3). While M-CHAT scores in the control group showed an overall decrease in total scores in 5 out of 7 participants post-intervention with an average percentage change of 11% (Figure 3.4).

Figure 3.3.

Comparison between baseline and post-intervention Total M-CHAT scores from individual participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5) with average percentage change.

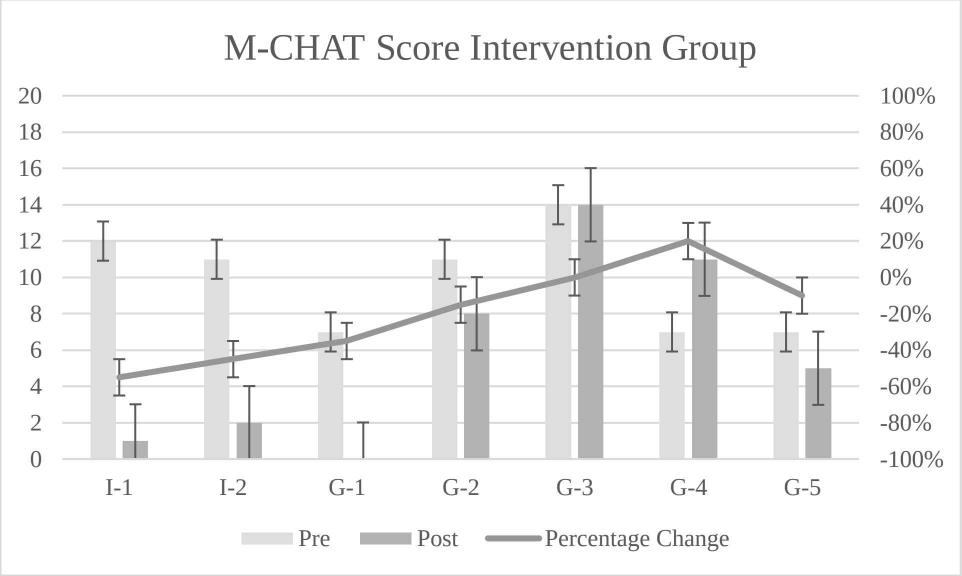
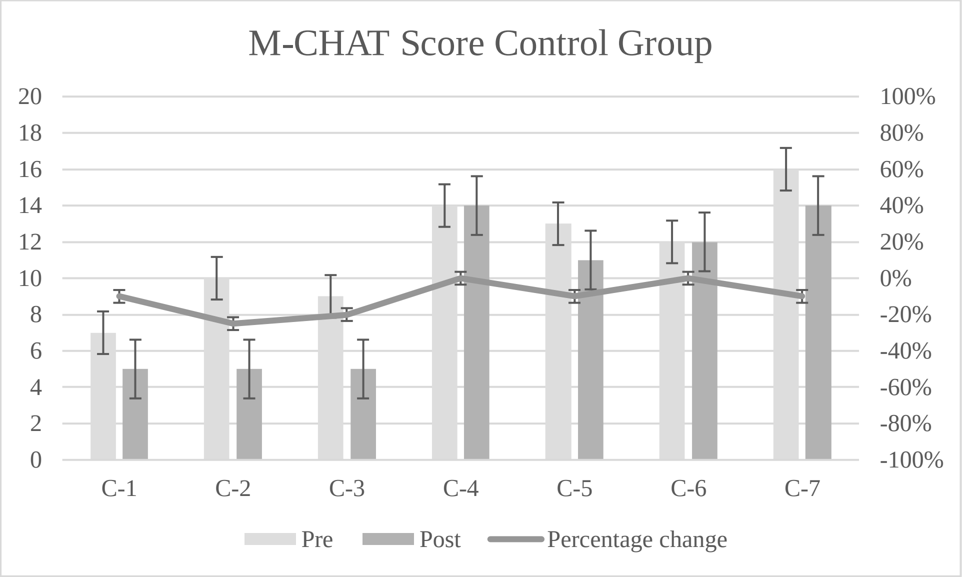


Figure 3.4.

Comparison between baseline and post-intervention Total M-CHAT scores from individual participants in control group (C-1 to C-7) with average percentage change.



Parent Reported Stress

Outcomes from APSI in both intervention group (see Figure 3.5) and control group (see Figure 3.6) did not show notable change in total parent stress scores post-intervention compared to baseline, with a small increase in average total percent change (2%) for participants in control group.

Figure 3.5.

Comparison between baseline and post-intervention Total parent stress scores from APSI in participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5) with average percentage change.

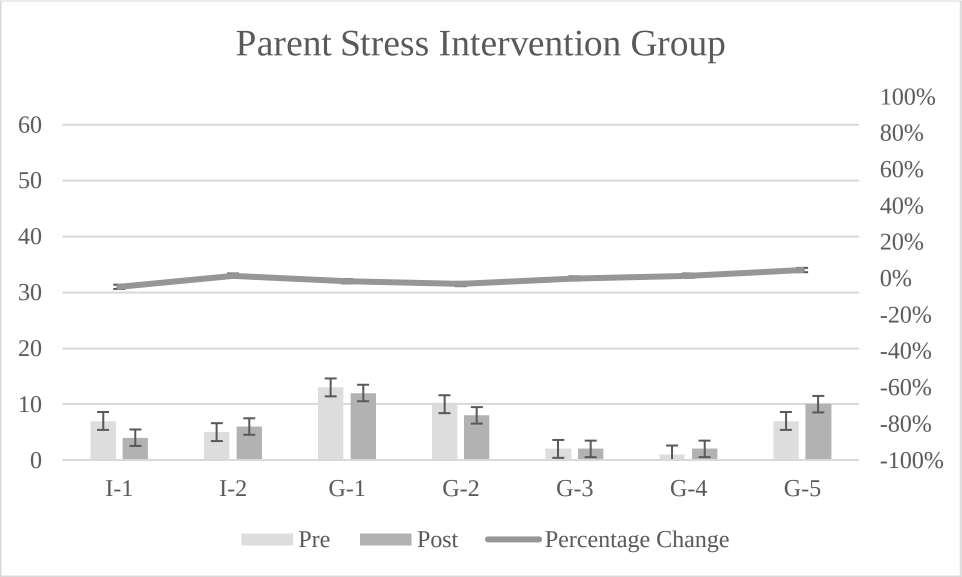
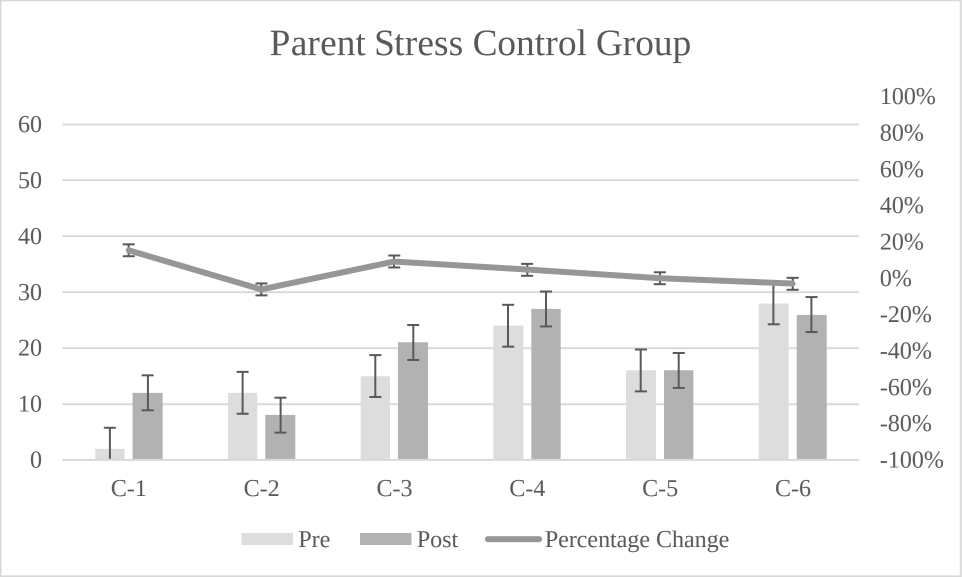


Figure 3.6.

Comparison between baseline and post-intervention Total parent stress scores from APSI in participants in control group (C-1 to C-6) with average percentage change.



Individual item scores from each sub-domain in the APSI for participants in intervention group (see Table 3.3) indicate that the highest stress scores were for the domains of ‘Core ASD Behaviours’ at both pre-intervention (M = 4, SD = 2.4) and post-intervention (M = 3.4 , SD = 1.6), as well as ‘Co-Morbid Challenging Behaviours’ at pre-intervention (M = 1.4, SD = 1.4) and post-intervention (M = 1.9 , SD = 1.5). This was also shown for participants in the control group (see Table 3.4) with stress scores reported for the domains of ‘Core ASD Behaviours’ at both pre-intervention (M = 8.9, SD = 5.5) and post-intervention (M = 9.6, SD = 4.4), as well as ‘Co-Morbid Challenging Behaviours’ at pre-intervention (M = 5.3, SD = 6.8) and post-intervention (M = 5.7, SD = 7.1).

Table 3.3.

APSI scores for 'Core ASD behaviours', 'Co-morbid challenging behaviours', and 'Co-morbid Physical behaviours' sub-domains at baseline and post-intervention for participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5).

Participant	**Core ASD**		**Co-morbid behaviours**		**Co-morbid physical**	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*
I-1	6	3	1	1	0	0
I-2	4	4	0	1	1	1
G-1	7	4	4	2	2	2
G-2	5	6	2	1	3	1
G-3	2	2	0	2	0	2
G-4	0	1	1	1	0	0
G-5	4	4	2	5	1	1
MEAN	4	3.4	1.4	1.9	1	1
SD	2.4	1.6	1.4	1.5	1.1	0.8

Table 3.4.

APSI scores for 'Core ASD behaviours', 'Co-morbid challenging behaviours', and 'Co-morbid Physical behaviours' sub-domains at baseline and post-intervention for participants in control group (C-1 to C-7).

Participant	Core ASD		Co-morbid behaviours		Co-morbid physical	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*
C-1	1	5	1	1	0	6
C-2	6	4	4	2	2	2
C-3	4	6	6	10	5	5
C-4	9	12	3	4	12	11
C-5	12	12	0	0	4	4
C-6	15	13	3	3	10	10
C-7	15	15	20	20	8	6
MEAN	8.9	9.6	5.3	5.7	5.9	6.3
SD	5.5	4.4	6.8	7.1	4.3	3.2

Family Experience

Outcomes from the AFEQ in Intervention group showed overall lower total scores for all participants with an average percent change of 8% post-intervention compared to baseline (see Figure 3.7), while average percent change in the total score for participants in the control group was 3% (see Figure 3.8).

Figure 3.7.

Comparison between baseline and post-intervention Total AFEQ scores in participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5) with average percentage change.

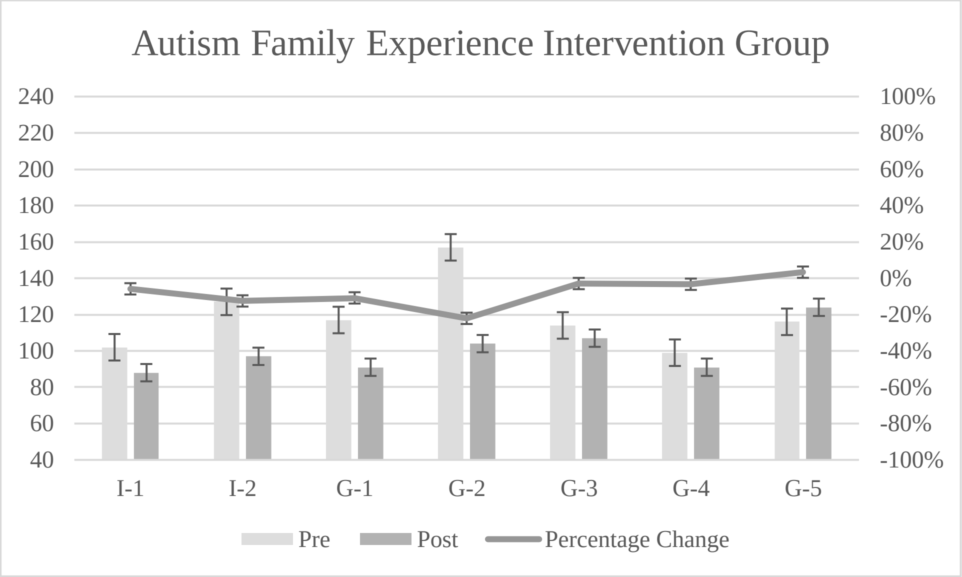
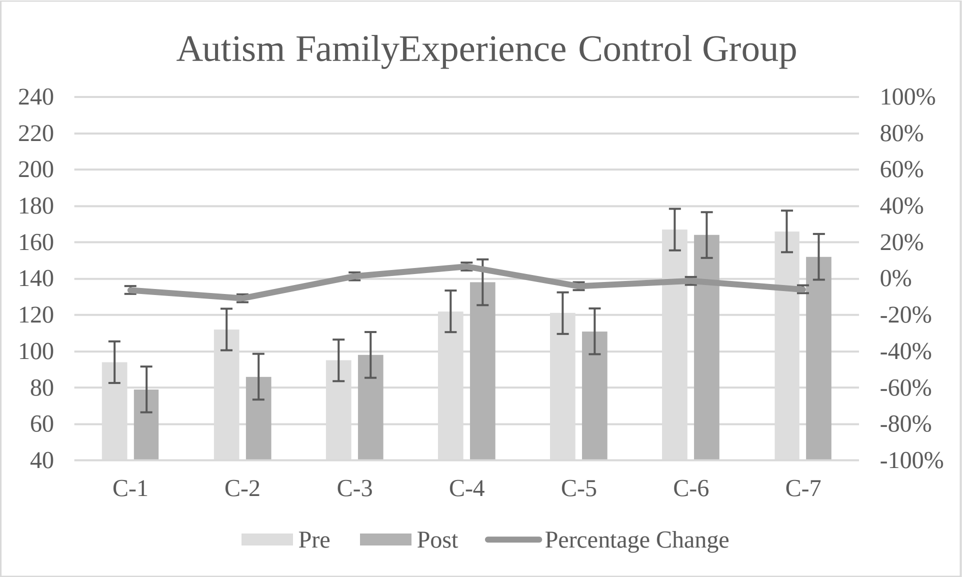


Figure 3.8.

Comparison between baseline and post-intervention Total AFEQ scores in participants in control group (C-1 to C-6) with average percentage change.



Individual item scores from each sub-domain in the AFEQ show an overall decrease in all four domains for participants in the intervention group, with most notable decrease in the domains of ‘Experience of being a Parent’ (From M = 34.3, SD = 6.2 to M = 27.3, SD = 6.4) and ‘Child Development, Understanding, and Social Reciprocity’ (From M = 37.4, SD = 7.4 to M = 31.1, SD = 5.9) (see Table 3.5). For participants in the control group, Individual item scores show slight improvement across all 4 domains (Table 3.6).

Table 3.5.

AFEQ scores for 'Experience of being a Parent', 'Family Life', 'Child Development, Understanding, and Social Reciprocity', and 'Child Symptoms' sub-domains at baseline and post-intervention for participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5).

Participant	**Experience of being a parent**		**Family life**		**Child dev., understanding, and social reciprocity**		**Child symptoms**	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
I-1	33	24	13	13	25	29	31	22
I-2	38	24	25	22	42	30	22	21
G-1	23	20	21	25	42	23	31	23
G-2	38	22	31	24	48	33	40	25
G-3	42	37	16	16	35	33	21	21
G-4	31	33	16	14	33	28	19	16
G-5	35	31	14	20	37	42	30	31
MEAN	34.2	27.3	19.4	19.1	37.4	31.1	27.7	22.7
SD	6.2	6.4	6.6	4.8	7.4	5.9	7.4	4.6

Table 3.6.

AFEQ scores for 'Experience of being a Parent', 'Family Life', 'Child Development, Understanding, and Social Reciprocity', and 'Child Symptoms' sub-domains at baseline and post-intervention for participants in the control group (C-1 to C-7).

Participant	**Experience of being a parent**		**Family life**		**Child dev., understanding, and social reciprocity**		**Child symptoms**	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
C-1	22	18	13	11	26	29	33	21
C-2	37	22	22	11	31	37	22	16
C-3	21	23	23	24	26	26	25	25
C-4	25	37	28	31	40	41	29	29
C-5	18	18	22	20	49	42	32	31
C-6	44	46	32	31	50	47	41	40
C-7	48	46	27	24	56	47	35	35
MEAN	30.7	30	23.9	21.8	39.7	38.4	31	28.1
SD	12.1	12.7	6.0	8.3	12.3	8.3	6.3	8.2

Parent Reported Social Communication Checklist

Outcomes from the SCC-R in the Intervention group showed an overall increase in total social communication scores in 6 out of 7 participants post-intervention compared to baseline, with an average increase of 7% (see Figure 3.9). Total social communication scores in the control also showed increase in 6 out of 7 participants, with an average increase in 4% (see Figure 3.10).

Figure 3.9.

Comparison between baseline and post-intervention Total Social Communication scores in participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5) with average percentage change.

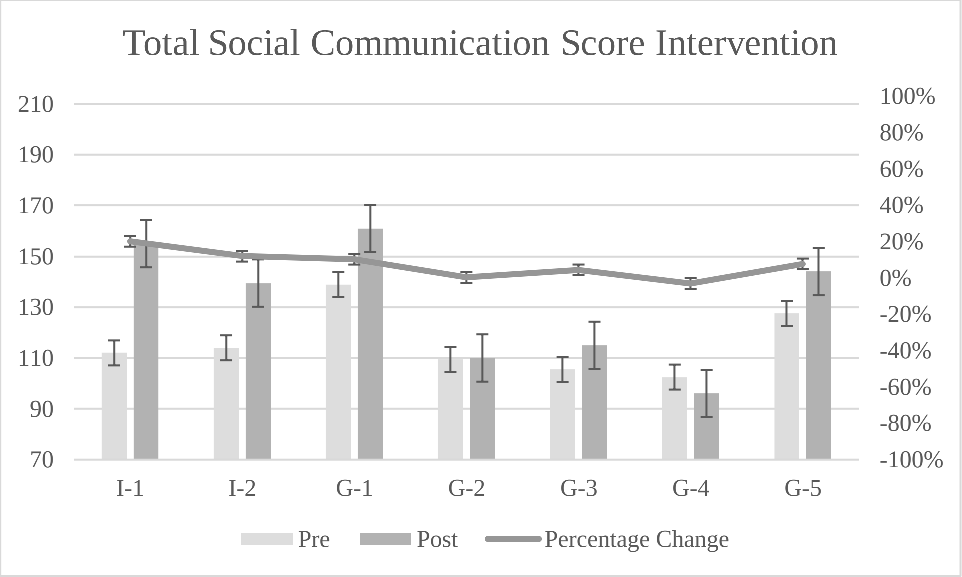
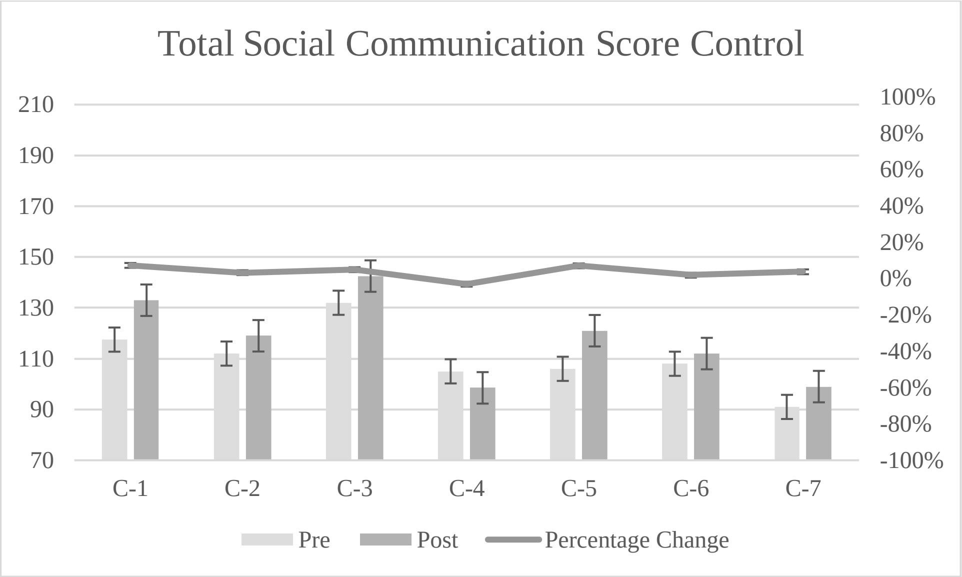


Figure 3.10.

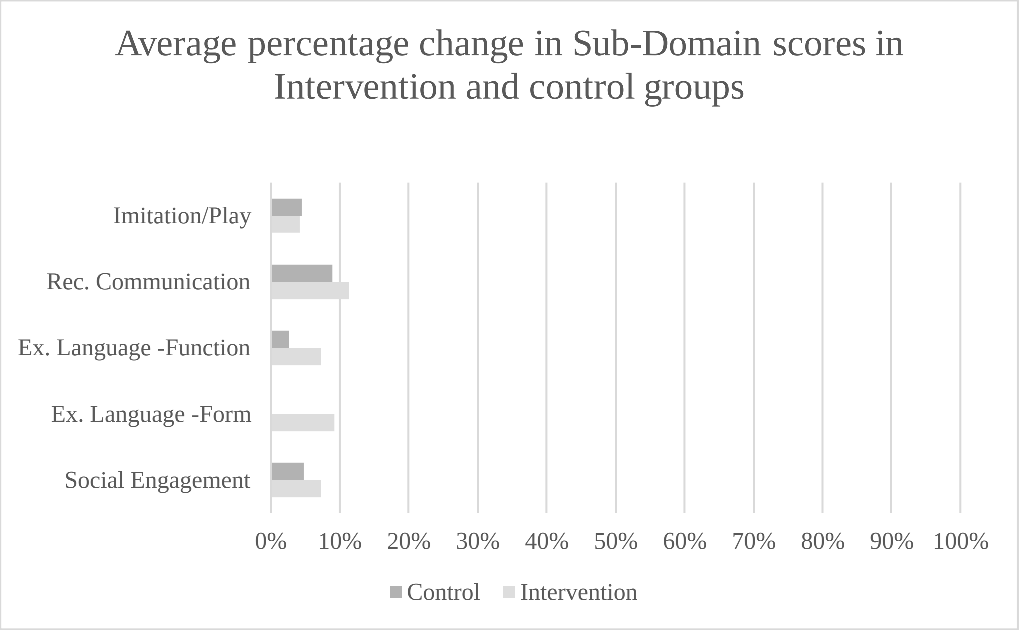
Comparison between baseline and post-intervention Total Social Communication scores in participants in control group (C-1 to C-6) with average percentage change.



Individual item scores from the SCC-R showed increase across all five sub-domains including ‘Imitation and Play’, ‘Receptive Communication’, ‘Expressive Communication – Function’, ‘Expressive Communication – Form’, and ‘Social Engagement’ post-intervention for all participants in intervention group and 6 out of 7 participants in the control group. Average percent increase was overall higher for participants in the intervention group (M = 7.8%) compared to the control group (M = 4.1%) , with most notable increase being the ‘Expressive Communication’, ‘Receptive Communication’, and ‘Social Engagement’ sub-domains (see Figure 3.11).

Figure 3.11.

Comparison between average percent change in SCC-R sub-domain scores post intervention in Intervention group and Control group.



Parent Knowledge of Behaviour and Environment

Outcomes from Behaviour Vignette showed increased total scores for all participants in the intervention group compared to baseline, with an average percent change of 29% (Figure 3.12). For participants in the control group, only 2 out of 7 participants showed an increase in total scores, with an overall lower average of scores (Figure 3.13).

Figure 3.12.

Comparison between baseline and post-intervention Total Behaviour Vignette scores in participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5) with average percentage change.

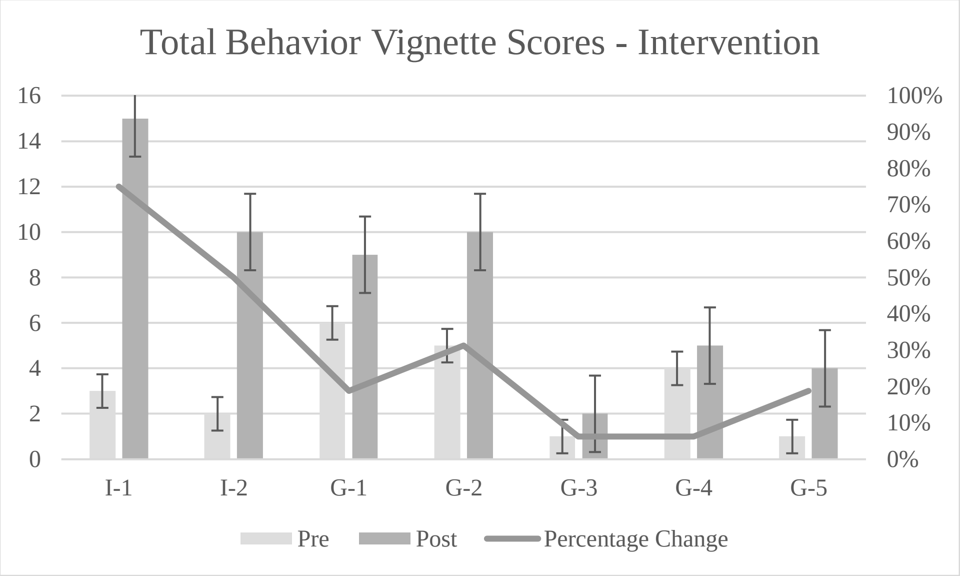
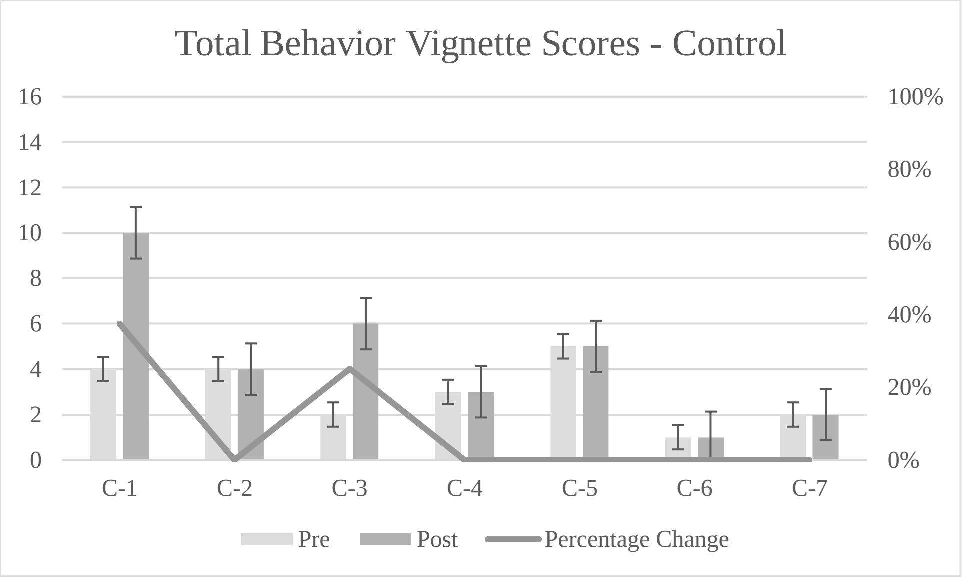


Figure 3.13.

Comparison between baseline and post-intervention Total Behaviour Vignette scores in participants in control group (C-1 to C-6) with average percentage change.



Outcomes from individual parameters used for scoring the behaviour vignette show that at baselines, participants in both intervention and control groups achieved their highest scores in the parameter for ‘Environmental Modifications’ (43% and 39% respectively), which was also the parameter with the highest and most improved scores post-intervention (93% and 57% respectively) (Table 3.7).

Table 3.7.

Average scores of Behaviour Vignette parameters for both Intervention and Control groups at baseline and post-intervention.

Average sub-parameter scores

Sub-domain	**Intervention**		**Control**	
	Pre	*Post*	*Pre*	*Post*
Identifying un-desired behaviour	11%	25%	7%	7%
Identifying environmental factors	14%	36%	21%	25%
Proposing alternative behaviour	11%	43%	7%	21%
Proposing environmental modifications	43%	93%	39%	57%

Treatment Acceptability

Outcomes from the TARF showed average acceptability score to be 97 (out of 119) and average percent of treatment acceptability to be 82% for participants in the intervention group (see Figure 3.14). For participants in the control group, the average acceptability score was found to be 82 (out of 119) with an average percent of treatment acceptability 69% for participants in the control group (see Figure 3.15).

Figure 3.14.

Total acceptability scores and acceptability percentage for participants in both I-CPMI (I-1 and I-2) and G-CPMI (G-1 to G-5).

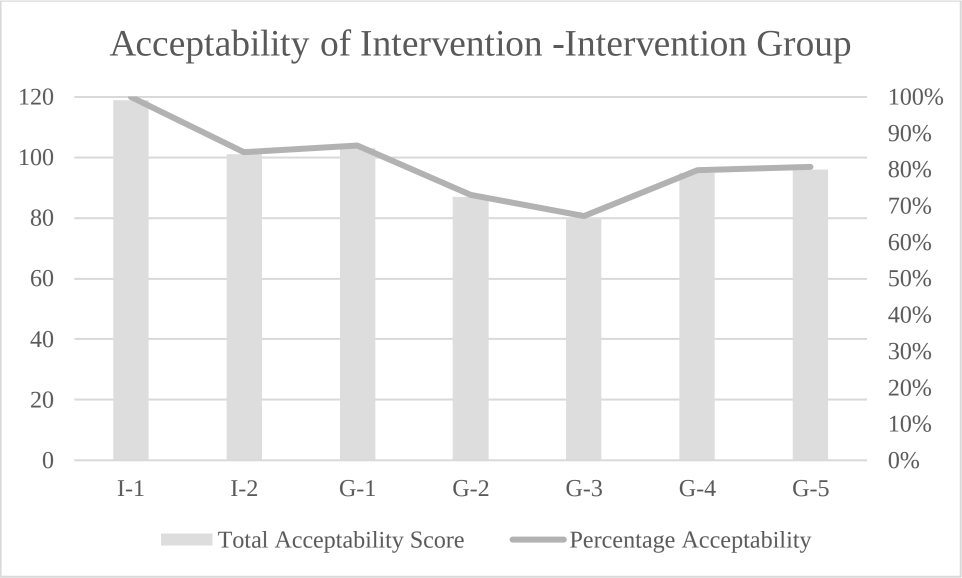
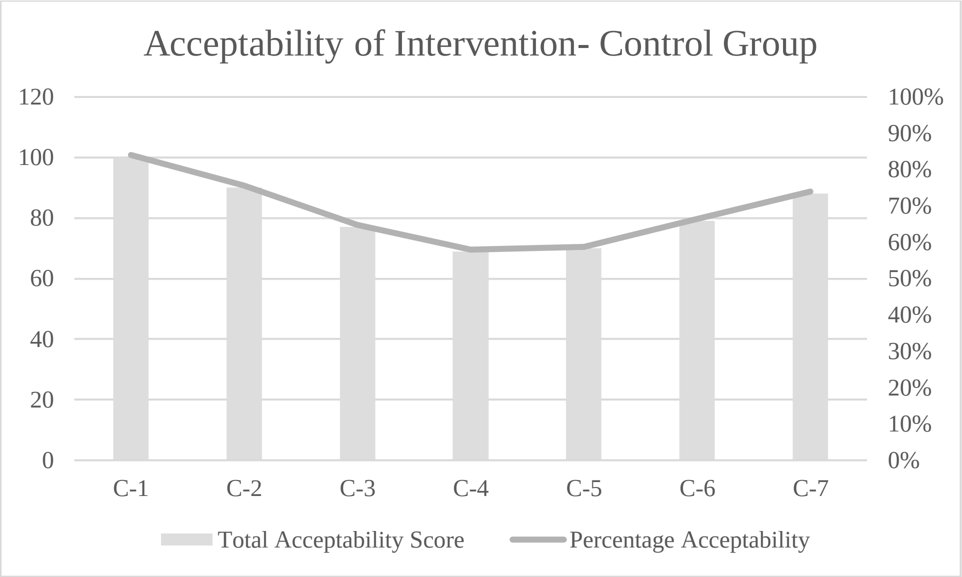


Figure 3.15.

Total acceptability scores and acceptability percentage for participants in control group (C-1-C-7).



Discussion

The present pilot study is the first randomised experimental study to explore parent-mediated intervention delivered via telehealth for toddlers ‘at risk’ of ASD in the UAE. The goal was to determine whether tele-coaching parents in the delivery of NDBI would be a feasible and acceptable approach to support parent-child engagement and learning throughout natural everyday activities at home. We also aimed to explore the impact of the modality of delivery on parent knowledge, engagement and reported change in their child’s social emotional behaviours. Outcomes from this study indicate an initial positive impact of tele-coaching parents in utilising NDBI strategies. These outcomes will be discussed in the context of participant socio-economic status, UAE culture, and preliminary indication on the ‘active ingredient’ of the intervention. The challenges and limitations of the study and implications on future research will also be explored.

While there were no significant changes in APSI total scores reported by participants in the intervention group, three participants in the control group reported higher total scores post-intervention, specifically within the sub-domains of 'Core ASD Behaviours' and 'Co-morbid Challenging Behaviours'. An increase in understanding of ASD features and awareness of challenging behaviours through the video modules, without access to a clinician's support with individual behaviour management strategies, may contribute to parents' feeling of stress.

Outcomes from the AFEQ indicate that participants from the intervention group reported the impact of 'Autism' on their family experience to be significantly lower post-intervention, specifically in their reported experience of being a parent, compared to participants in the control group. Offering tele-coaching sessions may enhance parents' understanding of how to support their child's development allowing them to feel more empowered and perceive their experience as being a parent in a more positive way. In a study done by Ingersoll et al. (2016), parents receiving therapist-assisted parent-mediated intervention through telehealth had a more positive perception of child with ASD compared to parents receiving self-directed intervention.

Participants in the intervention group also reported higher total SCC-R scores and greater improvement in their child's social engagement, expressive, and receptive communication compared to parents in the control group. This supports our hypotheses that parent coaching further enhances parents' acquisition of skills that may foster improved parent-child engagement by offering immediate feedback and reflection and more individualised support.

Although parents in both intervention group and control group reported some improvement in the 'imitation and play' sub-domain of SCC-R, this was minimal compared to the gains in the other sub-domains. It is important to consider that within the cultural context of the UAE, some parents are often unsure of how to engage in play with their children (Personal correspondence, Al Jalila Children's Specialty Hospital, 2021). Also, teaching play skills may benefit from more demonstration or role play, which was challenging without the presence of the child.

Outcomes from the Behaviour Vignette were analysed according to 4 parameters to ascertain parents' knowledge of behaviour and the environment. While all participants in the intervention group showed improved overall knowledge, the 2 participants from the I-CPMI achieved the highest gains with a percentage change of 75% and 50%, compared to the parents in the G-CPMI who achieved gains between 6-31%. It is also worth mentioning that the two participants who scored the highest gains amongst the G-CPMI are the participants with the highest session attendance rates (100% each). Attending coaching sessions may have provided more opportunities for the participants to discuss examples and receive individual feedback from the clinician which may have solidified the learning. Participants in the control group who only had access to the modules did not show similar gains. These outcomes support the hypothesis that the parent coaching sessions is an active ingredient in the intervention.

In terms of which parameters were the most improved, participants in both intervention and control groups achieved the highest gains in their knowledge of 'Environmental Factors', 'Alternative Behaviours' and 'Environmental Modifications', however, these parameters were also noted to be the highest at baseline, compared to their knowledge of 'Un-desired Behaviours'. This suggests that parents may be more attentive to factors in the environment rather than knowledge of the potential challenges or skill deficits their child may have. Considering that all participants were parents of children on the 'wait list' for assessment with no confirmed diagnosis, it can be expected that their knowledge of ASD related behaviours may be limited, which additionally supports our findings.

Participants from both Intervention and control groups reported the intervention to be acceptable. Despite 3 of the 5 participants in G-CPMI having lower attendance levels, their reported outcomes from the TARF indicate that they found the intervention to be ‘reasonable’, ‘effective’ and that they were ‘willing’ to participate with no significant ‘cost’, ‘side-effects’ or ‘disruptiveness’ reported. This supports the reasons given by parents for missing the scheduled sessions, which was due to “illness” or being “busy”.

There were some challenges in carrying out this pilot study. Initially, the biggest challenge was the recruitment of the participants. Out of 52 potential participants that met criteria, only 26 were interested in participating, out of which only 19 signed consents. Despite having toddlers ‘flagged’ for concern of ASD, around half of the parents either believed that their child did not need intervention prior to a formal diagnosis, or that they needed intervention by a professional rather than a parent. This does not come as a surprise, as the Arab population in the Middle East believe in a medical model of disability, with little emphasis given on the social environment. It may also suggest that despite increased awareness of ASD in the UAE, there continues to be a degree of stigma associated with a diagnosis of ASD, and that by accepting intervention they are indirectly accepting that their child may be diagnosed.

Regarding the characteristics of the 19 participants. Despite being balanced in terms of nationality, location, and employment status, the majority of participants in the intervention group were older in age, had more children, and of a higher education level. These differences in participant characteristics between the intervention group and control group must be considered when interpreting the results.

Further, the high rate of attrition and the low number of participants in the intervention groups presented a major challenge as it was not possible to compare outcomes from the individual (I-CPMI) with the group-based (G-CPMI) intervention arms.

Results from the current pilot study support the preliminary feasibility of a brief parent-mediated intervention delivered via telehealth for toddlers ‘at risk’ of ASD in the UAE. While there were limitations to the current pilot, including: small sample size; high rate of attrition; and use of parent-reported measures, outcomes are utilised in the development of the next phase of our research program. It is important to mention that it was difficult to determine the generalisability of the skills learned by parents, since no direct observation of parent-child dyads was conducted during intervention, as it was outside of the scope of this study. Developing a ‘best fit’ model for a parent-mediated intervention delivered via telehealth within the context of the UAE will need to consider an adaptive design that incorporates easier access and a shorter intervention to improve parent engagement in intervention, as well as a stepped-care approach that is adaptable to parents’ needs.

Chapter 4

An Adaptive Parent-Mediated NDBI Program Delivered via Telehealth - A Sequential Multiple Assignment Randomized Trial

Autism Spectrum Disorder affects individuals and their families around the world. Despite a growing body of data supporting interventions that target the acquisition of certain skills, there continues to be a gap in knowledge in understanding what interventions work within different contexts. In response to this challenge, a recent position statement published by the Lancet Commission on the Future of Care and Clinical Research in Autism, proposed an adaptive/stepped care model of intervention that considers the individual differences of individuals with autism, their families, and their social and cultural contexts, in order to improve outcomes (Lord et al., 2021). Indeed, research that facilities immediate impact on the improvement of individuals with Autism and their families' lives across diverse communities and cultures must be prioritised.

When considering positive outcomes and improvement in the quality of lives of young children with Autism and their families, it is important to understand how a 'stepped care' approach can support the acquisition of skills and the minimising of any barriers to learning that may be present. Considering the broad heterogeneity in children with Autism, it is important to examine the effect different sequences of intervention strategies may have on child outcomes, family outcomes and how early response to treatment may predict these outcomes (Lord et al., 2021). One research design that holds promise in bridging the gap between research and clinical practice and has been applied in Autism research is the Sequential Multiple Assignment Randomized Trials (SMART) (Almirall et al., 2014; Kasari et al., 2014). The SMART design allows for the systematic application of a combination of intervention components, including the modality of delivery, dose, and treatment augmentation, through making data-based decisions during the intervention. This is done through assigning recipients to different sequences of interventions at specific time points based on the status of their response, which facilitates an individualised stepped-care approach within an adaptive intervention. Indeed, adaptive interventions are useful in settings and populations where: not everyone responds to the same intervention; response to intervention changes over time; and when effective interventions are not available to everyone due to limited resources (Nahum-Shani and Almirall, 2019, Yan et al. 2021).

While Randomized Control Trials (RCTs) are considered the gold standard in evaluating effectiveness of developed interventions (Lauffenburger et al., 2022), the SMART design is a useful experimental tool to use when building an adaptive intervention (Buchholz et al., 2020), and can be a superior choice when conducting research with small sample sizes (Yan et al., 2021). SMART designs can be used to answer many questions regarding the selection and integration of components, including what intervention to offer initially; what subsequent interventions can be offered to augment or increase intensity when indicated; and what sequence is best (Nahum-Shani & Almirall, 2019). In line with implementation science theory, utilising an adaptive experimental design such as the SMART can allow for more rapid evaluation and delivery of optimal interventions and bridge the gap between evidence-based research and clinical practice (Lauffenburger et al., 2022).

In Chapter 3, outcomes from a pilot study examining the effects of individual and group-based tele-coaching of parent-mediated NDBI delivered to parents of toddlers ‘at risk’ of Autism in the UAE were discussed. While the results supported the initial feasibility of a brief parent-mediated intervention delivered via telehealth for parents of toddlers with social communication challenges awaiting diagnostic assessment within the context of the UAE, there were some barriers and limitations that need to be considered to determine a ‘best fit’ model of intervention. Outcomes from the pilot study emphasise the importance of an adaptive approach that is more easily accessible to parents, is shorter in duration, and addresses the variability and individual differences between the children, their parents, and the family context.

The current chapter provides an examination of an adaptive, stepped-care, approach in the delivery of parent-mediated NDBI via telehealth, utilising a SMART design, as part of the next phase of this research program. Specifically, we aimed to investigate a) the optimal sequence for a brief adaptive intervention of coaching parent-mediated NDBI through telehealth; b) the optimal intensity for augmenting intervention for parents identified as slow responders to intervention; c) impact of a combination of online modules and asynchronous tele-coaching on parent knowledge and engagement compared to modules alone; d) the feasibility and acceptability of the adaptive intervention.

Method

Participants and Setting

The current study was conducted in 2022 at Al Jalila Children's Specialty Hospital located in Dubai, United Arab Emirates. This was a follow-up to a pilot study conducted by the primary investigator at the same site. Amendments to initial ethical approval obtained by Trinity College Dublin, School of Psychology, were approved in April 2022. Following a change in the hospital's regulatory authority in 2022 from Dubai Healthcare City to Dubai Health Authority, amendments to initial ethical approval were submitted to the Dubai Scientific Research Ethics Committee – Dubai Health Authority and were approved in August 2022. There were no adverse events reported in the current study.

The Al Jalila Children's Specialty Hospital waitlist of children 'under four years' awaiting diagnostic evaluation was scanned for participants. In addition, General Paediatricians working at the hospital were approached to share their list of patients to be referred for social communication disorders, which were also scanned for participants. Parents were contacted by phone and invited to participate if : a) they had a child between 18-36 months, identified as ‘at risk’ of ASD or diagnosed with ASD, scoring as positive during screening with M-CHAT (total score > 7); b) they were residents of urban and non-urban areas with no access to licensed ABA service providers; c) same parent was available to attend training during the 6-week intervention period; d) they had a camera enabled electronic device with home access to an internet connection; e) were English and/or Arabic speaking.

Out of 55 parents that met inclusion criteria, 23 parents were interested in participating and were sent the information sheets, recruitment letters, and consent forms by e-mail, after which 21 parents signed consent to participate in the study. During the intervention phase of the study, one parent withdrew their participation and a total of 20 participants completed the study.

All 20 participants in both the Modules only group (M) and Modules in addition to Asynchronous Parent Coaching (M+APC) group were mothers who were married. Most participants were between the ages 30-39 years old, had two or more children, and were of Emirati or Arab descent. Participants in the M+APC group had higher levels of education and majority were employed. Table 4.1 below summarises the demographic data of all participants.

Table 4.1

Summary of Participant Demographic Data from both the modules only group and the modules plus Asynchronous Parent Coaching group.

Characteristics	**Modules only (%)**	**Modules+APC (%)**
Gender		
Male	0 (0)	0 (0)
Female	9 (100)	11 (100)
Age		
20-29 years	2 (22)	0 (0)
30-39 years	7 (78)	10 (90)
40-49 years	0 (0)	1 (10)
Nationality		
Emirati	6 (67)	5 (46)
Arab	2 (22)	3 (27)
Other	1 (11)	3 (27)
Emirate of Residence		
Dubai	2 (22)	7 (64)
Other Emirate	7 (78)	4 (36)
Education level		
High School	4 (45)	2 (18)
College	1 (11)	0 (0)
Undergraduate	2 (22)	6 (55)
Graduate	2 (22)	3 (27)
Number of Children		
1	1 (11)	0 (0)
2	4 (45)	6 (55)
3	2 (22)	0 (0)
>3	2 (22)	5 (45)
Employment		
Full/Part-Time	2 (22)	8 (73)
Un-employed	7 (78)	3 (27)
Preferred Language		
Arabic	6 (67)	5 (45)
English	3 (33)	6 (55)

Design

The current study adopted a Sequential Multiple Assignment Randomized Control Trial (SMART) with pre/post-test. Consenting participants (n-21) completed baseline outcome measures and questionnaires (T1). They were then randomly assigned, using a random number generator (www.randomlists.com), into one of two groups who received a different sequence of interventions: a) weekly pre-recorded video modules only (M) (n=10); b) weekly modules in addition to Asynchronous Parent Coaching through individualised video recordings (M+APC) (n=11). At week three (T2), participants completed a rapid assessment of response to intervention, based on which they were identified as Responders (R) or Slow Responders (SR). Participants identified as SR from both groups were re-randomised into sub-groups, using a random number generator, and received different forms of augmented intervention. At week 6 (T3), participants completed post-intervention outcomes measures.

Measures

Pre-intervention measures (T1): All pre-intervention baseline measures were completed by parent participants with the support of the primary investigator. Outcome measures were completed over the phone and were provided in both English and Arabic based on Parent's preferred language.

a) Demographic Questionnaire: A 9-item bilingual questionnaire was developed by the primary investigator to collect participant demographics including their gender, age, relationship status, nationality, place of residence, education status, number and age of children, employment status.
b) Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al., 2014): The M-CHAT is a parent completed screening tool used to identify behaviours associated with ASD. Internal consistency is adequate (Cronbach's alpha 0.79). The M-CHAT was used as a pre-intervention measure to identify children 'at-risk' and as a baseline measure for comparison post-intervention. The Arabic translation of the M-CHAT is available and has been previously validated (Eldin et al., 2008).
c) Autism Family Experience Questionnaire (AFEQ) (Leadbitter et al., 2018): The Autism Family Experience Questionnaire (AFEQ) measures broader

impact of an intervention on the family, including experience being a parent (Cronbach's alpha 0.85), family life (0.83), child development (0.81), child symptoms (0.79), with an AFEQ total score (0.92). Permission to use the AFEQ and approval of Arabic back translation was received by its lead author (Dr. Kathy Leadbitter) in October 2021.

d) Social Communication Checklist-Revised (SCC-R) (Weiner et al., 2017): SCC-R is a 70-item checklist completed by parents to indicate if their child uses skills related to social engagement, expressive and receptive communication, and imitation/play. Internal consistency and test-re-test reliability were found to be good to excellent (Cronbach's alpha 0.985 for total score, Interclass correlation 0.855). Permission to use the SCC-R and approval of Arabic back translation was received by its lead author (Dr. Allison Weiner) in October 2021.

e) Behaviour Vignette (Arnold et al., 2003): The protocol was developed by the Research Units on Paediatric Psychopharmacology Autism Network and has demonstrated high levels of agreement between expert raters with Intraclass Correlation Coefficient of 0.895 across a panel of five raters (Arnold et al., 2003). A Behaviour Vignette relevant to the content of the intervention was created in both Arabic and English and used as a measure of acquired knowledge. Participants were presented with four different scenarios and undertook a detailed semi-structured interview during which they identified problem behaviours and potential behavioural functions. A score of '1' is given for each response that was an example of 'Identifying Un-desired Behaviour', 'Identifying Environmental Factors' contributing to behaviour, 'Proposing Alternative Behaviour', and 'Proposing Modification to the

Environment' within each of the four scenarios. A score of '0' is given for the absence of response. The scores are tallied for each participant (with a maximum attainable total score of 16).

Mid-intervention measure (T2):

The Status Survey was completed at week 3 as a rapid measure of response to intervention to identify slow responders and initiate next phase of intervention.

a) Status Survey (SS): A 10-item rating form was developed as a rapid measure of response to intervention. Items related to different intervention targets were rated on a 5-point scale ranging from 'much less', 'a little less', 'no change', 'a little more' and 'much more' and were assigned a score from 1-5 respectively. Total score was calculated as a percentage and participants were identified as 'responders' (>80%) or 'non-responder' (<80%). This form was adapted from the Clinical Global Impression form (Guy, 1976), which is a 7-point rating scale developed to provide a global impression of progress in targeted outcomes during intervention sessions in a fast, easy, and reliable way to facilitate systematic and rapid decisions on augmentations in intervention (Busner & Targum, 2007).

Post-intervention measures (T3):

All post-intervention measures were completed by participants on the phone following the completion of the 6-week intervention cycle. In addition to the measures completed at T1 (M-CHAT, AFEQ, SCC-R, Behaviour Vignette, SS) the below measures were also completed:

a) Acceptability of Intervention Measure (AIM)/ Intervention Appropriateness Measure (IAM)/ Feasibility of Intervention Measure (FIM) (Weiner et al., 2017): AIM/IAM/FIM is a 12-item scale that measure Acceptability (4 items), Appropriateness (4 items) and Feasibility (4 items). Test-retest reliability coefficients ranged from 0.73 to 0.88. and Cronbach α's from 4 items scales were 0.85 to 0.91.

b) Attitude and Engagement in Intervention Questionnaire (AEIQ): A 25-item semi-structured questionnaire was developed as a measure of engagement in the different components of intervention and to identify possible facilitators or barriers. Qualitative data were analysed for common emerging themes.

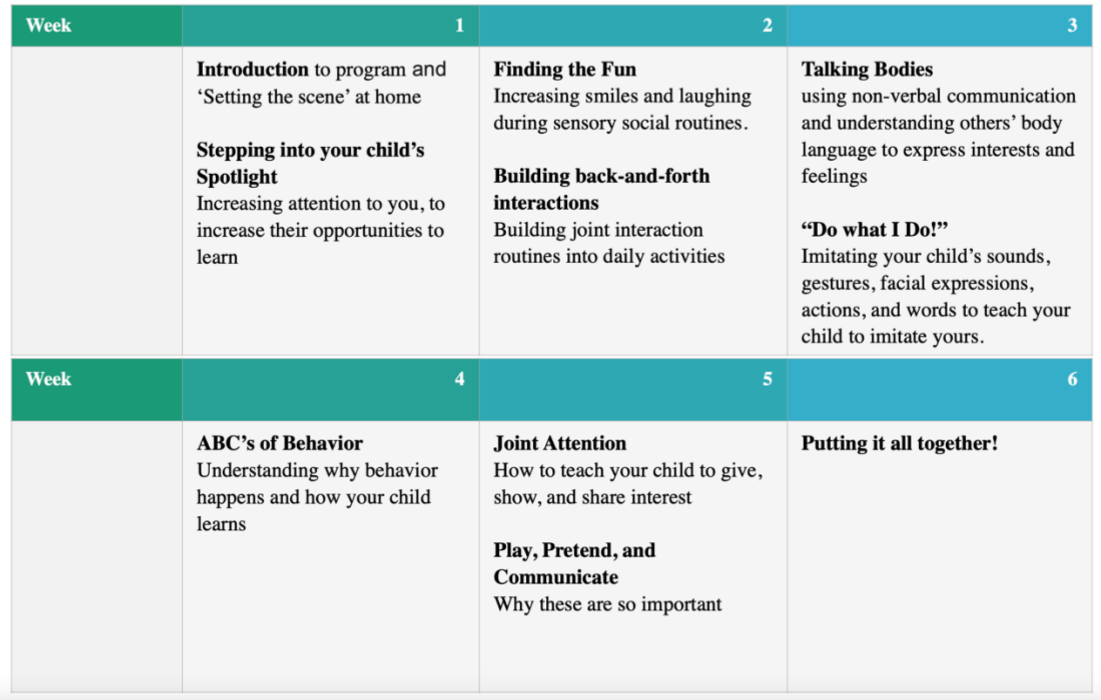
Procedure

The 6-week intervention program was carried out in three phases. During Phase 1 of the program, all participants received a 'welcome message' sent individually through 'WhatsApp' social media application from a business account accessed via a password protected mobile device dedicated to the study. The welcome message included a brief outline of the program and instructions on accessing the video modules. The ten learning modules assigned were developed and pre-recorded by the primary investigator as discussed in Chapter 2. They were distributed into each of the six weeks, with most weeks combining two themes based on the length of presentations and relevance and relatedness of the content (see Figure 4.1).

In addition to the video presentation links shared weekly through 'WhatsApp', participants were also sent a self-evaluation checklist of the strategies taught for that week. Participants in the 'M+APC' group were encouraged to complete it and were offered additional support in the form of brief asynchronous tele-coaching video recordings, sent individually through 'WhatsApp', to support with any concepts that were found to be challenging as identified by the self-evaluation checklist.

Figure 4.1.

Outline of weekly themes targeted in the 6-week intervention cycle.



Week	1	2	3
	Introduction to program and 'Setting the scene' at home **Stepping into your child's Spotlight** Increasing attention to you, to increase their opportunities to learn	**Finding the Fun** Increasing smiles and laughing during sensory social routines. **Building back-and-forth interactions** Building joint interaction routines into daily activities	**Talking Bodies** using non-verbal communication and understanding others' body language to express interests and feelings **"Do what I Do!"** Imitating your child's sounds, gestures, facial expressions, actions, and words to teach your child to imitate yours.
Week	**4**	**5**	**6**
	ABC's of Behavior Understanding why behavior happens and how your child learns	**Joint Attention** How to teach your child to give, show, and share interest **Play, Pretend, and Communicate** Why these are so important	**Putting it all together!**

During phase 2 of the intervention program, which was at the end of week 3, participants were sent the Status Survey to complete (T2). Based on the outcomes, participants that were identified as 'responders' according to pre-set criteria continued to receive the same intervention. Participants that were identified as 'slow responders' were re-randomised into one of two sub-groups receiving augmented intervention in the form of either: a) a single Rescue Synchronous Parent Coaching session (R-SPC); or b) Weekly Synchronous Parent Coaching sessions (W-SPC).

During phase 3, all participants continued to receive their weekly modules. Participants identified as 'responders' continued to receive either modules only for group 'M', or modules in addition to asynchronous parent coaching for group 'M+APC'. Participants identified as 'slow responders' who were randomly assigned to the 'R-SPC' group received, the weekly modules in addition to a single 1.5-hour synchronous tele-coaching session scheduled at week 4, while participants who were randomly assigned to the ‘W-SPC’ group received the weekly modules in addition to weekly 1.5-hour synchronous tele-coaching sessions scheduled for the remainder of the intervention (weeks 4-6). The scheduled synchronous tele-coaching sessions were conducted through the Microsoft Teams application, the link for which was shared on WhatsApp. While the sessions were structured to start with reflecting on some of the challenges identified through the status survey, they were also collaborative and offered an opportunity to discuss individualised approaches to implementing the strategies based on parents’ context.

Following the 6-week intervention cycle, a total of 20 participants completed the program and post-intervention outcomes measures (T3). One participant withdrew from the ‘M’ group at week 4, after being identified as a ‘slow responder’, due to having ‘no time’ to continue with the intervention and refusing the scheduled tele-coaching session (see Figure 4.2). Table 4.2 provides a summary of acronyms used to describe different phases of the intervention program.

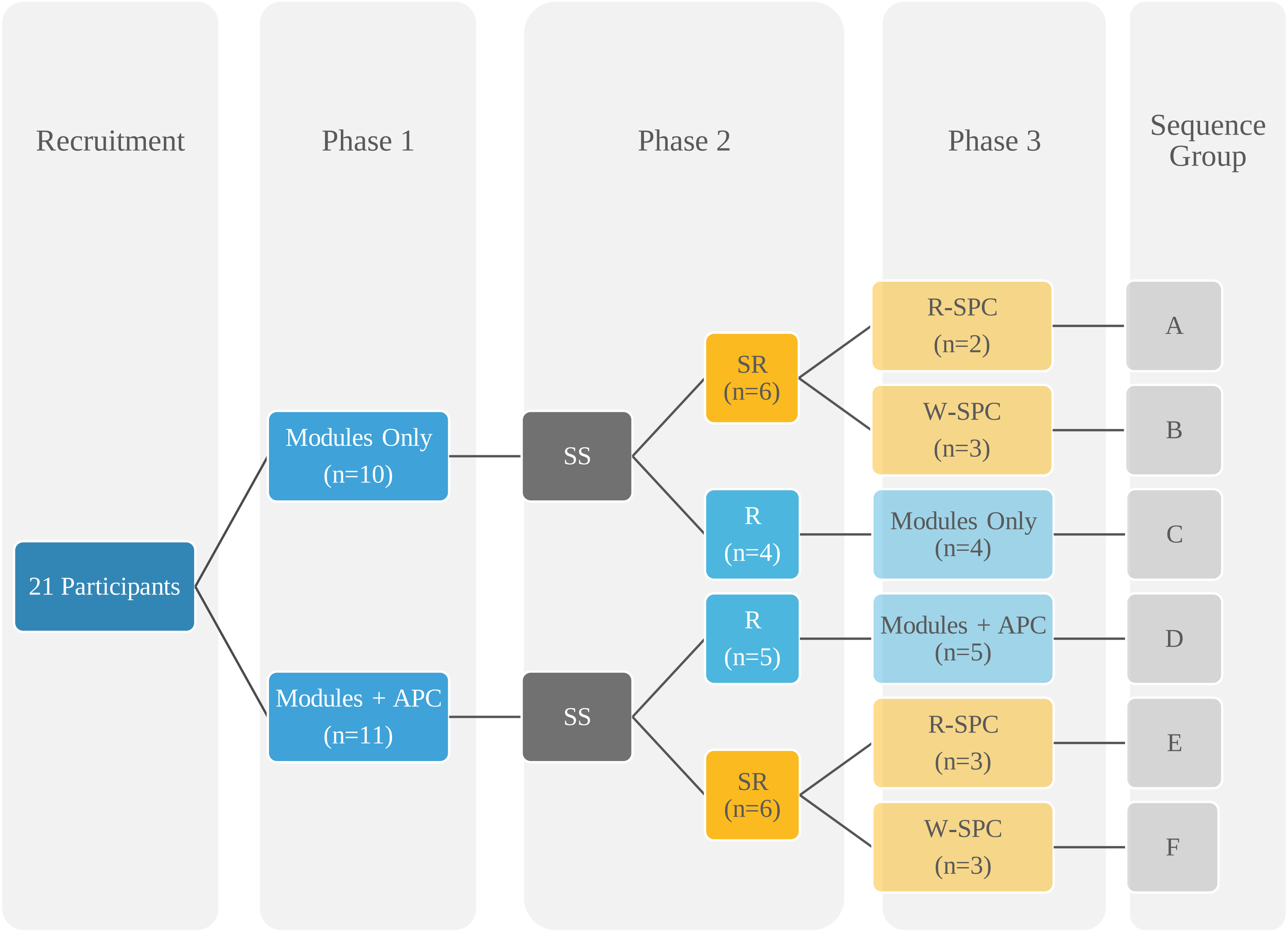
Table 4.2.

Summary of acronyms used to describe phases of intervention and participant groups.

Acronym	Explanation
MODULES ONLY	Pre-recorded video modules only
MODULES + APC	Pre-recorded video modules + Asynchronous Parent Coaching sessions
SS	Status Survey
SR	Slow Responder
R	Responder
R-SPC	Rescue Synchronous Parent Coaching session
W-SPC	Weekly Synchronous Parent Coaching sessions

Figure 4.2

Flow-chart of the SMART design implemented through three phases of the intervention program.



Data Analysis

Pre- and post-intervention data from participants were presented based on sequence of adaptive intervention received (see Table 4.3). Comparative analysis was conducted to identify the main effect according to the aims of the current study including optimal sequence, intensity, and decision rules for augmentation of intervention. This method of data analysis has been conducted in similar SMART designs in behavioural intervention research (Almirall et al., 2014).

Table 4.3

Description of each participant and their assigned group based on the final sequence of intervention received.

Participant	Sequence group
A-1	A
A-2	
B-1	B
B-2	
B-3	
C-1	C
C-2	
C-3	
C-4	
D-1	D
D-2	
D-3	
D-4	
D-5	
E-1	E
E-2	
E-3	
F-1	F
F-2	
F-3	

In the interest of clarity, data from the Attitude and Engagement in Intervention Questionnaire are analysed qualitatively and are presented and discussed in depth in Chapter 5 in order to provide an in-depth analysis of emerging themes from the current study.

Results

Attendance

Data on the attendance of participants throughout the intervention were collected for all participants receiving coaching sessions for the duration of the 6-week cycle. This included participants that received sequences A (n= 2), B (n= 3), E (n= 3), and F (n= 3) (see Table 4.4). It is important to mention that for participants in sequence groups 'E' (n=3) and 'F' (n=3) who were allocated to receive Asynchronous Parent Coaching (APC) in addition the modules, only one participant (F-2) was provided with short APC videos throughout the intervention cycle based on their engagement and expression of interest in additional support.

Nine out of the eleven participants in groups A, B, E, and F, who were scheduled to receive either Rescue (R) coaching sessions or Weekly (W) coaching sessions, had 100% attendance rates. One participant in sequence group 'B' did not attend any of their scheduled weekly sessions, citing "being busy" as their reason for refusing the sessions. One participant in sequence group 'F' missed one session due to being 'sick'.

Table 4.4

Attendance of participants in groups A, B, E, and F for scheduled Rescue (R) or Weekly (W) coaching sessions during weeks 4-6 of the intervention cycle.

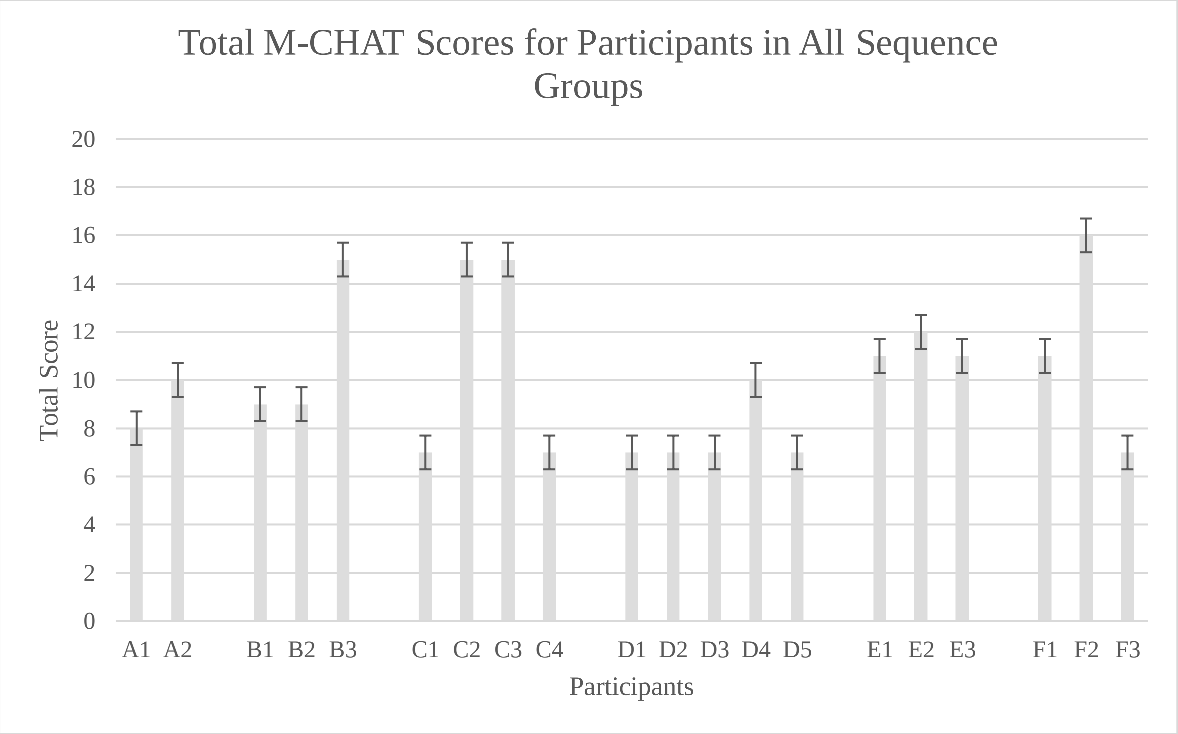
Participant	Week			Total attendance (%)
	4	*5*	*6*	
A-1	+ (R)			100%
A-2	+ (R)			100%
B-1	+ (W)	+ (W)	+ (W)	100%
B-2	+ (W)	+ (W)	+ (W)	100%
B-3	-	-	-	0%
E-1	+ (R)			100%
E-2		+ (R)		100%
E-3	+ (R)			100%
F-1	+ (W)	-	+ (W)	67%
F-2	+ (W)	+ (W)	+ (W)	100%
F-3	+ (W)	+ (W)	+ (W)	100%

Identification of Behaviours Associated with Autism

Data collected from M-CHAT were used to assess risk for ASD at baseline (see Figure 4.3). All participants scored above the cut-off score (>7), with the lowest score reported to be 7 and the highest score being 16. Participants in sequence group ‘D’ had a lower mean score (M=7.6, SD=1.34), compared to participants in sequence group ‘A’ (M= 9, SD=1.41), sequence group ‘B’ (|M=11, SD=3.46), sequence group ‘C’ (M=11, SD=4.62), sequence group ‘E’ (M= 11.33, SD= 0.58), and sequence group ‘F’ (M= 11.33, SD= 4.50). A one-way ANOVA was performed to evaluate the relationship between sequence groups and M-CHAT scores at baseline. The ANOVA was not significant at the 0.05 level, F (5,14) = 0.98, p = 0.464.

Figure 4.3

Total M-CHAT scores for individual participants in sequence groups A-F at baseline (T1).



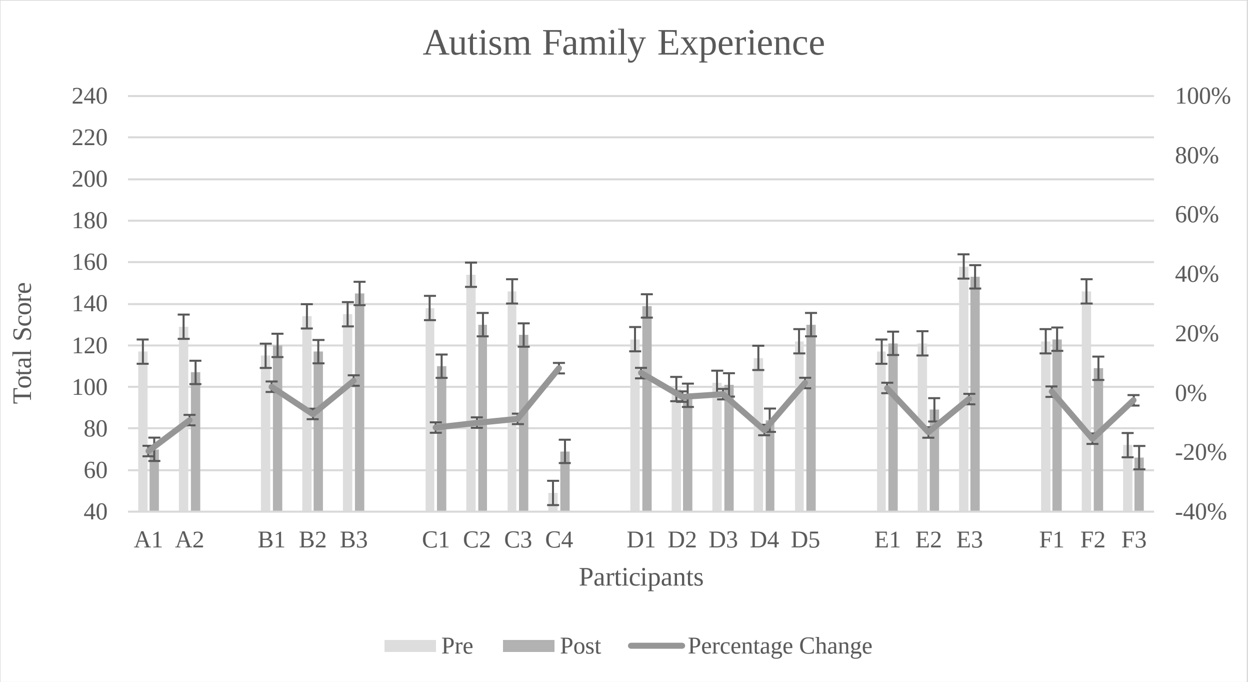
Family Experience

Post-intervention outcomes from the AFEQ were compared to baseline for all participants in sequence groups A-F (see Figure 4.4). Two participants in sequence group ‘A’ showed a decrease in total scores from baseline with an average percent change of 14%. One out of the three participants in sequence group ‘B’ showed a decrease in total scores by 7% post intervention, while two showed slightly increased scores, resulting in an average percent change of 0% for that group. For group ‘C’, three out of four participants showed lower scores post intervention, while one reported a higher total score, averaging at 6% change. Two out of five participants in group ‘D’ showed a decrease in total scores, two reported higher total scores, while one participant reported no change post-intervention, resulting in an average percentage change of 1%. For group

‘E’, two out of 3 reported lower scores, with an average percentage change of 5%. Finally for group ‘F’, two out of three participants reported lower scores, while one participant reported no change post-intervention, resulting in an average percentage change of 6%. A one-way ANOVA was performed to evaluate the relationship between sequence groups and percentage change. The ANOVA was not significant at the 0.05 level, F (5,14) = 1.09, p = 0.409.

Figure 4.4

C*omparison between baseline and post-intervention Total AFEQ scores for participants in sequence groups A, B, C, D, E and F, with average percentage change.*



Individual item scores from each sub-domain in the AFEQ show an overall decrease in mean scores in all four domains for participants in groups ‘A’, ‘E’, and ‘F’. The most notable decrease was reported in group ‘A’ in the domains of ‘Child development, understanding and social reciprocity’ (From M= 44.0, SD=2.8 to M=34.0, SD=2.8) and ‘Child symptoms’ (From M= 30.0, SD=1.4 to M=18.5, SD=4.9). Mean sub-domains scores reported for group ‘B’ show a slight increase in the domain of ‘Family Life’ (From M=21.7, SD=4.5 to M=24.3, SD=3.1), but a decrease in scores for other sub-domains. In group ‘C’, there was a minor increase in the domain of ‘Experience of being a parent’ (From M= 25.0, SD=13.0 to M=26.5, SD= 8.9), while there was a decrease in all other sub-domains, most notably the ‘Child development, understanding, and social reciprocity’ (From M=44.3 , SD=16.2 to M=35.5 , SD=7.7). Mean sub-domain scores for group ‘D’ show a minor decrease the ‘Experience of being a parent’ (From M= 32.6, SD= 8.6 to M= 29.0, SD= 8.9), as well as a minor increase in the ‘Child symptoms’ domain (From M= 25.8, SD= 3.1to M= 27.6, SD= 4.8). Table 4.5 below presents a summary of sub-domain scores for participants in sequence groups A-F.

Table 4.5

AFEQ scores for ‘Experience of being a Parent’, ‘Family Life’, ‘Child Development, Understanding, and Social Reciprocity’, and ‘Child Symptoms’ sub-domains at baseline and post-intervention for participants in sequence groups A-F, with Mean (M) and Standard Deviation (SD) per group.

Participant	**Experience of being a parent**		**Family life**		**Child dev., understanding & social reciprocity**		**Child symptoms**	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
A1	21	10	19	13	46	32	31	15
A2	34	28	24	21	42	36	29	22
M	***27.5***	***19.0***	***21.5***	***17.0***	***44.0***	***34.0***	***30.0***	***18.5***
SD	***9.2***	***12.7***	***3.5***	***5.7***	***2.8***	***2.8***	***1.4***	***4.9***
B1	32	24	17	21	39	34	27	41
B2	28	26	26	25	46	41	34	25
B3	30	36	22	27	50	51	33	31
M	***30.0***	***28.7***	***21.7***	***24.3***	***45.0***	***42.0***	***31.3***	***32.3***
SD	***2.0***	***6.4***	***4.5***	***3.1***	***5.6***	***8.5***	***3.8***	***8.1***
C1	33	29	25	16	46	39	34	26
C2	36	35	28	25	53	39	37	31
C3	24	28	28	28	57	40	37	29
C4	7	14	6	9	21	24	15	22
M	***25.0***	***26.5***	***21.8***	***19.5***	***44.3***	***35.5***	***30.8***	***27.0***
SD	***13.0***	***8.9***	***10.6***	***8.7***	***16.2***	***7.7***	***10.6***	***3.9***
D1	33	34	25	28	34	42	31	35
D2	24	27	16	19	33	26	26	24
D3	24	28	21	20	33	29	24	24
D4	39	16	21	14	31	29	23	25
D5	43	40	20	20	34	40	25	30

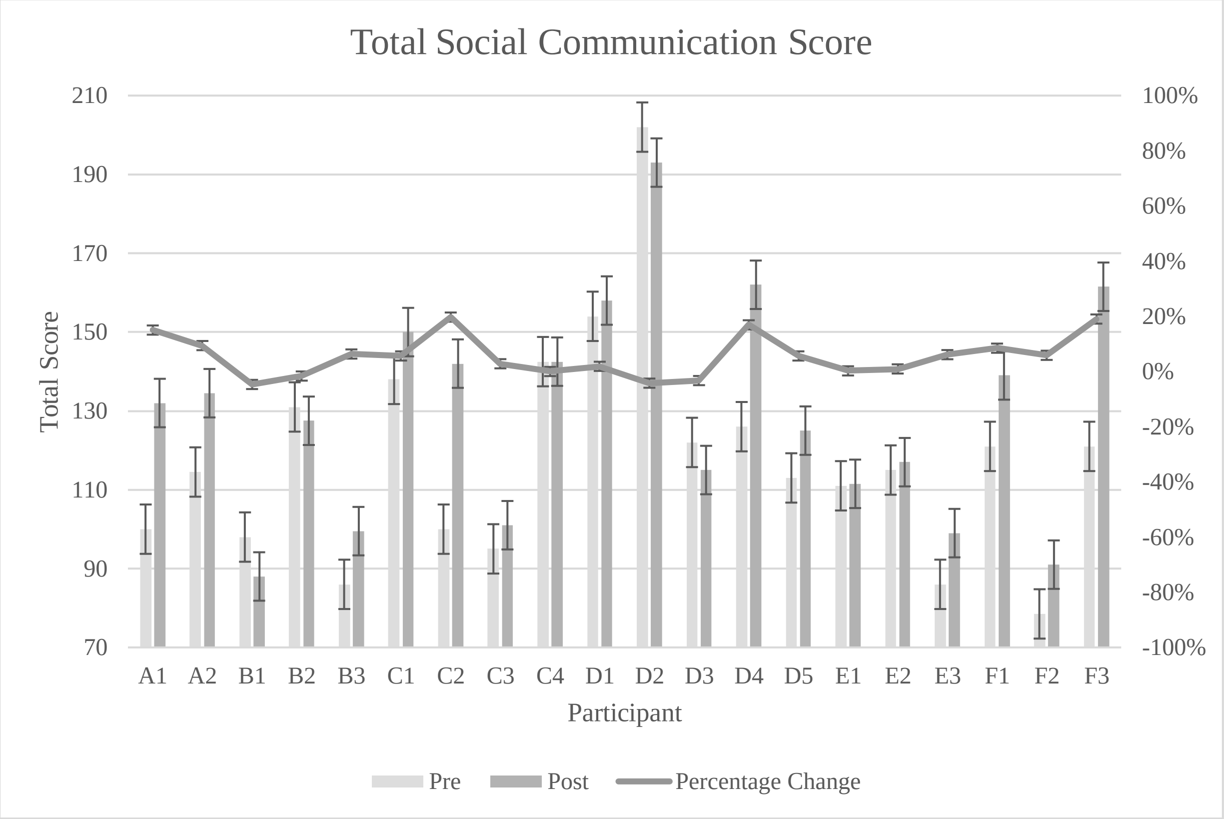
	M	***32.6***	***29.0***	***20.6***	***20.2***	***33.0***	***33.2***	***25.8***	***27.6***
	SD	***8.6***	***8.9***	***3.2***	***5.0***	***1.2***	***7.3***	***3.1***	***4.8***
E1		32	33	21	17	35	42	29	29
E2		29	20	18	14	52	37	22	18
E3		38	38	28	25	51	48	41	42
	M	***33.0***	***30.3***	***22.3***	***18.7***	***46.0***	***42.3***	***30.7***	***29.7***
	SD	***4.6***	***9.3***	***5.1***	***5.7***	***9.5***	***5.5***	***9.6***	***12.0***
F1		40	31	17	23	39	43	26	26
F2		38	32	21	12	59	42	28	23
F3		22	17	11	8	18	21	21	20
	M	***33.3***	***26.7***	***16.3***	***14.3***	***38.7***	***35.3***	***25.0***	***23.0***
	SD	***9.9***	***8.4***	***5.0***	***7.8***	***20.5***	***12.4***	***3.6***	***3.0***

Social Communication Checklist-Revised (Parent Reported)

Outcomes from the SCC-R showed an overall increase in total social communication scores in 14 out of the 20 participants compared to baseline, while four participants reported a decrease (from sequence groups ‘B’ and ‘D’), and two participants reported no change post-intervention (from sequence groups ‘C’ and ‘E’). The highest average percent change was seen for sequence groups ‘A’ and ‘F’, with mean percent change scores of 12% and 11%, respectively. Figure 4.5 below provides a visual presentation of pre- and post-intervention total social communication scores for each participant in sequence groups A, B, C, D, E, and F.

Figure 4.5

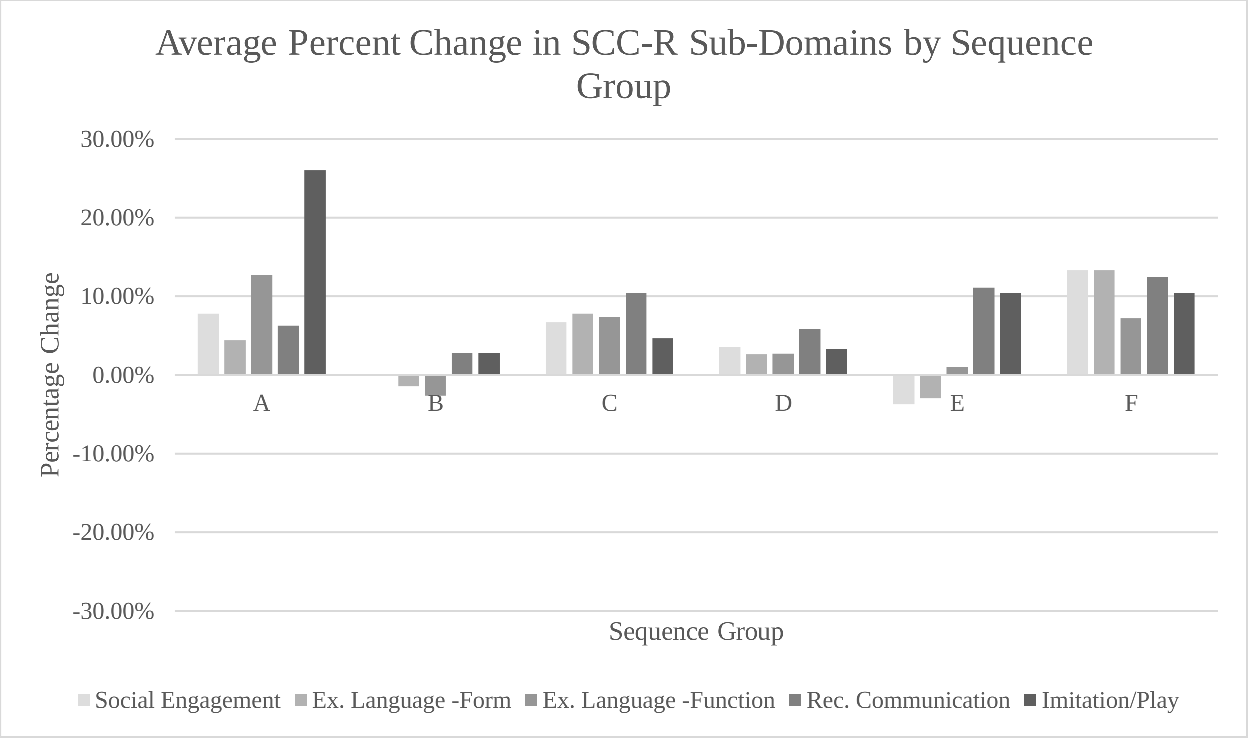
Comparison between baseline and post-intervention Total Social Communication scores in participants in participants from sequence groups A-F with average percentage change.



A comparison of average percent change for individual SCC-R sub-domains demonstrates improvement for all six sequence groups (A, B, C, D, E, and F) for the sub-domains of ‘Receptive Communication’, with the highest percent change for group ‘F’ (13%), and ‘Imitation/Play’, with the highest percent change for group ‘A’ (26%). For the ‘Social Engagement’ sub-domain, improvements were shown in sequence groups ‘A’ (7.8%), ‘C’ (6.7%), and ‘D’ (4%), while group ‘E’ showed an average percent change of -4%. For the sub-domains of ‘Expressive Language-Form’ and ‘Expressive Language-Function’, Group ‘B’ reported lower average scores post intervention, while groups ‘A’, ‘C’, ‘D’ and ‘F’ showed improvements. Figure 4.6 below shows the average percentage change for all six sequence groups for each sub-domain.

Figure 4.6

Comparison between average percent change in SCC-R sub-domains post-intervention for sequence groups A, B, C, D, E, and F.

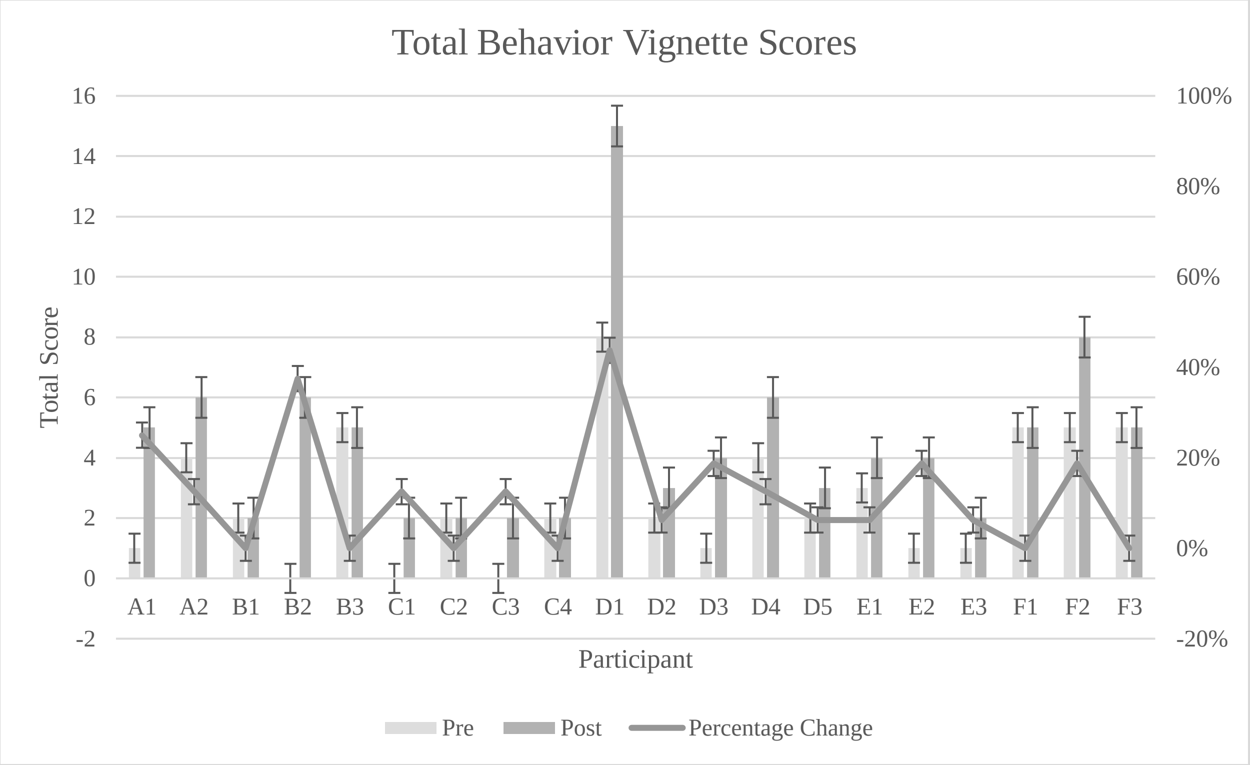


Parent Knowledge of Behaviour and Environment

Outcome from the Behaviour Vignette showed increased total scores for 14 out of 20 participants compared to baseline, while six participants from groups 'B' (n=2), 'C' (n=2), and 'F' (n=2) showed no change (see Figure 4.7). The highest percentage change was seen in Participants D1 (44%), B2 (38%), and A1 (25%).

Figure 4.7

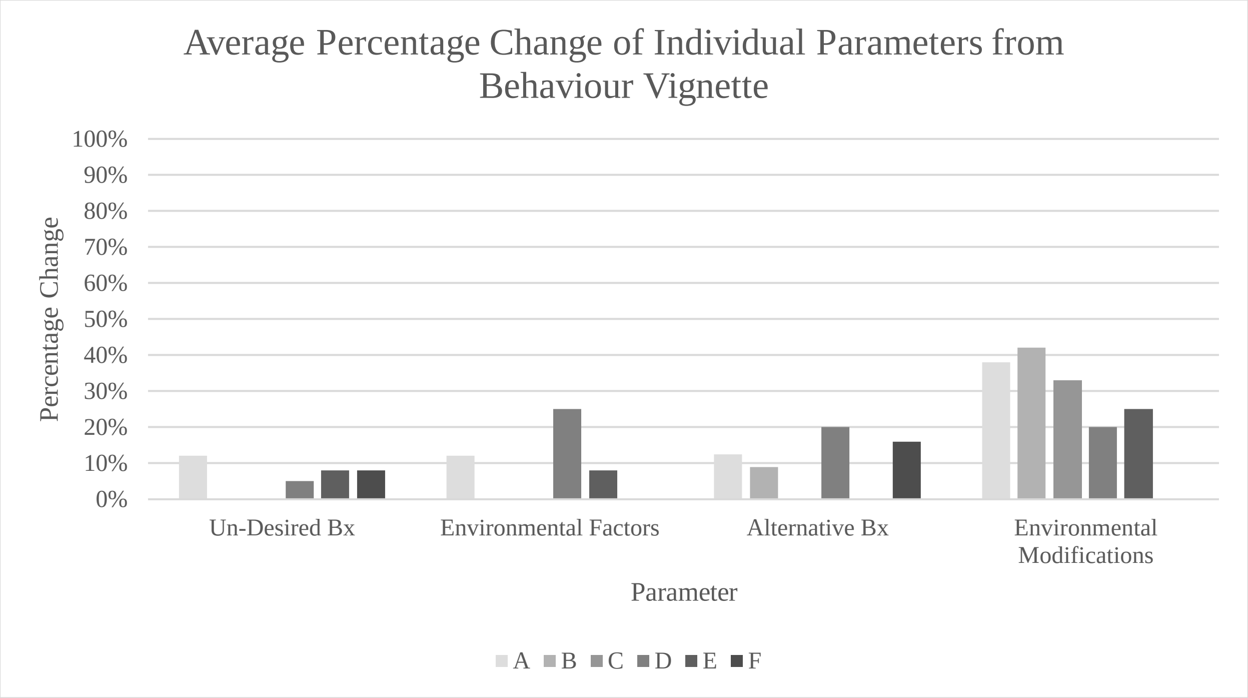
Comparison between baseline and post-intervention Total Behaviour Vignette scores in participants from sequence groups A, B, C, D, E, and F with average percentage change.



Outcomes from individual parameters used for scoring the behaviour vignette show that the parameter with the highest average percentage change for sequence groups A (M=38%), B (M=42%), C (M=33%), D (M=20%), and E (25%) was ‘Proposing Environmental Modifications’. This is followed by the parameter of “Proposing Alternative Behaviours’ with average percentage change scores of 13% (group ‘A’); 9% (group ‘B’); 20% (group ‘D’); and 16% (group ‘F’). Figure 4.8 below presents the average percentage change for sequence groups A-F by parameter.

Figure 4.8

Average percentage change of Behaviour Vignette individual parameter scores for sequence groups A, B, C, D, E, and F.



Acceptability, Appropriateness and Feasibility of Intervention

Participants in all sequence groups generally reported favourable ratings (i.e., >4) for the AIM (M= 4.39, SD= 0.43), IAM (M= 4.29, SD= 0.45), and FIM (M= 4.24, SD= 0.40) scales (see Table 4.6). Total scores were calculated, showing overall percentage of Acceptability, Appropriateness and Feasibility of intervention to be > 80% for all participants, with average score of 87% (see Figure 4.9).

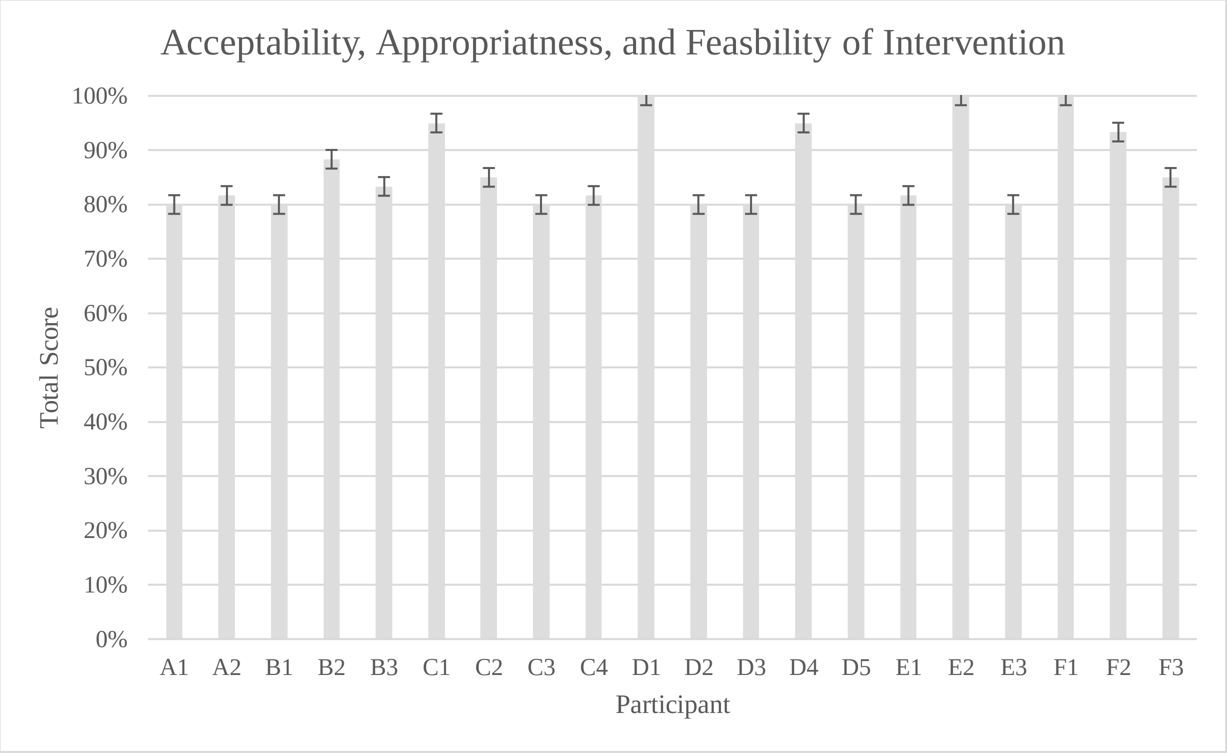
Table 4.6

Mean scores of Acceptability (AIM), Appropriateness (IAM), and Feasibility (FIM) of intervention received for individual participants in sequence groups A, B, C, D, E, and F.

Participant	AIM	IAM	FIM
A1	4.00	4.00	4.00
A2	4.25	4.00	4.00
B1	4.00	4.00	4.00
B2	5.00	4.25	4.00
B3	4.25	4.00	4.00
C1	5.00	5.00	4.25
C2	4.00	4.50	4.25
C3	4.00	4.00	4.00
C4	4.75	3.50	4.00
D1	5.00	5.00	5.00
D2	4.00	4.00	4.00
D3	4.00	4.00	4.00
D4	4.75	4.50	4.00
D5	4.00	4.00	4.00
E1	4.25	4.00	4.00
E2	5.00	5.00	5.00
E3	4.00	4.00	4.00
F1	5.00	5.00	5.00
F2	4.25	4.75	5.00
F3	4.25	4.25	4.25
MEAN (SD)	**4.39 (0.43)**	**4.29 (0.45)**	**4.24 (0.40)**

Figure 4.9

Total score (%) for Acceptability, Appropriateness, and Feasibility of Intervention for participants in sequence groups A, B, C, D, E, and F.



Response to Intervention

The Status Survey (SS) was administered two times during the six-week cycle, once at week 3 (T2) as a rapid assessment of response to the intervention, followed by another time post-intervention (T3) for comparison. At week 3, five participants from the ‘M’ only group (A1, A2, B1, B2, and B3), and six participants from the ‘M+APC’ group (E1, E2, E3, F,1, F2, and F3) were identified as ‘slow responders’ for scoring < 80% on the total SS score (see Table 4.7).

Table 4.7.

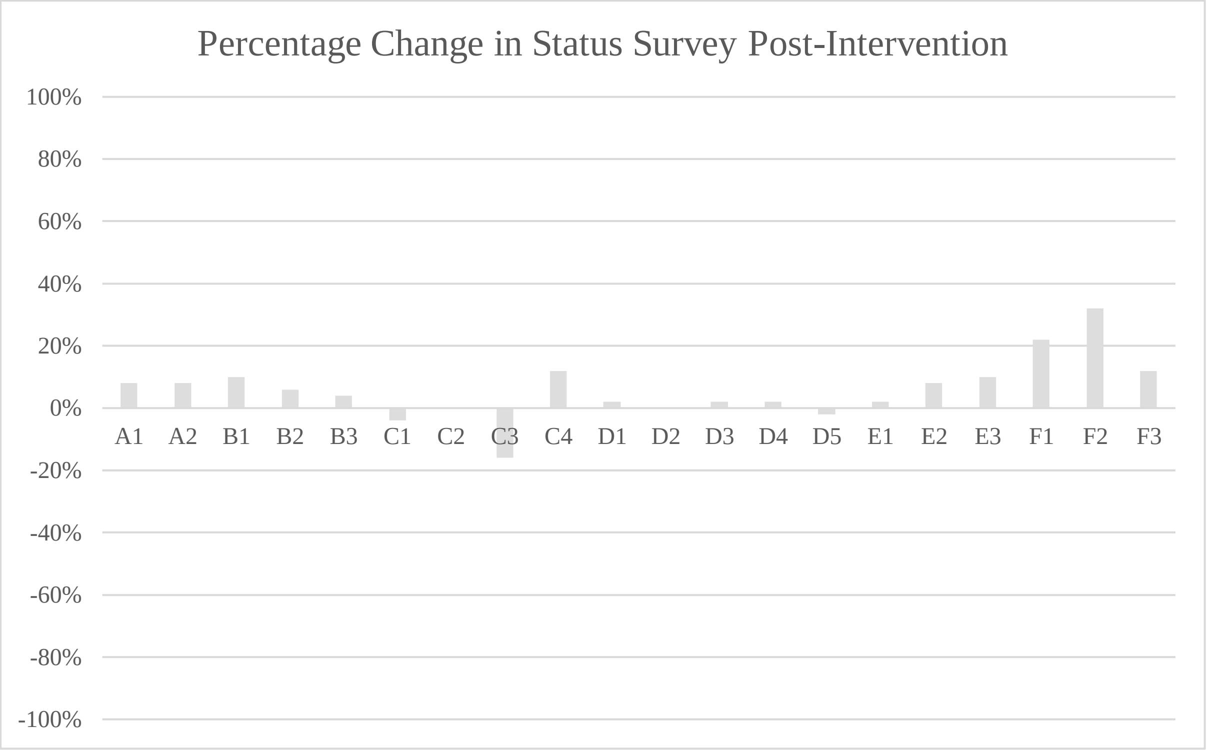
Total scores (%) from Status Survey administered Mid-Intervention (T2) and Post-Intervention (T3) for individual participants in sequence groups A, B, C, D, E, and F.

Participant	**Status Survey Sotal Score (%)**	
	Mid-Intervention (T2)	*Post-Intervention (T3)*
A1	72%	80%
A2	78%	86%
B1	68%	78%
B2	74%	80%
B3	78%	82%
C1	80%	76%
C2	82%	82%
C3	80%	64%
C4	80%	92%
D1	88%	90%
D2	82%	82%
D3	80%	82%
D4	82%	84%
D5	80%	78%
E1	78%	80%
E2	72%	80%
E3	60%	70%
F1	74%	96%
F2	60%	92%
F3	78%	90%

A comparison of week 3 and post-intervention SS total scores (see Figure 4.10) show that the highest percentage change was reported by participants identified as ‘non-responders’ in sequence groups ‘A’ (8% and 8%); ‘B’ (10%, 6%, and 4%); ‘E’ (2%, 8%, and 10%), with the greatest improvement seen in group ‘F’ (22%, 32%, and 12%). Participants identified as ‘responders’ were reported to have a lower range of percentage change (from 0% to 12%), with two participants from groups ‘C’ (C1, -4%; and C3, -16%) and one from group ‘D’ (D5, -2%) showing lower scores post-intervention compared to scores from week 3. A one-way ANOVA was performed to evaluate the relationship between sequence groups and percentage change in SS scores. The ANOVA was significant at the 0.05 level, F (5,14) = 4.92, p = 0.008.

Figure 4.10

Percentage change of total SS scores from mid-intervention (T2) to post-intervention (T3) for participants in sequence groups A, B, C, D, E, and F.



Discussion

The present study was a follow-up to the pilot evaluation trial discussed in Chapter 3 and is the second experimental study of our research program investigating parent-mediated interventions delivered via telehealth for toddlers ‘at risk’ of ASD in the UAE. Outcomes from the pilot study informed the current study, whereby a SMART design was utilised to understand the feasibility and acceptability of an adaptive ‘stepped care’ model of delivering tele-coaching of parent-mediated NDBI and its impact on parent-child engagement. The goal was to determine the optimal sequence, intensity, and modality of delivering the intervention, as well as to better understand how to adapt this based on parents’ response during the intervention. We also aimed to explore the impact of different adapted sequences of intervention on parent knowledge and child social emotional behaviours. Outcomes from this study suggest that following an adaptive 'best fit' model for delivery of intervention is a suitable approach that promotes parent engagement in intervention as well and enhances parent knowledge and utilisation of NDBI teaching strategies. These outcomes will be discussed in the context of parents' initial response to intervention, and preliminary indication of the optimal sequence for an adaptive stepped-care model. The challenges and limitations of the study and implications on future research will also be explored.

In terms of the impact of Autism on the family experience, outcomes from the AFEQ indicate that participants that were identified as 'non responders' and received augmented intervention (sequence groups, A, E, and F) reported the most improvement. This improvement was reported across all domains, most notably in the domain of 'Child Development, Understanding and Social reciprocity', as well as 'Autism symptoms' for sequence group A. While participants identified as 'responders' to intervention and continued to receive modules only (sequence groups C and D) also reported improvement, this was minimal compared to groups A, E and F. This suggests that augmenting the intervention with synchronous parent coaching may optimise parents' understanding of how to best support their child's development, in turn perceiving their child more positively and experiencing a lesser burden on the family. This is in line with findings from our pilot study, discussed in chapter 3, as well as previous studies that reported a more positive perception of their child with ASD following therapist-assisted parent-mediated intervention delivered through telehealth (Ingersoll et al., 2016). While participants in sequence group B also received synchronous parent coaching, outcomes from the AFEQ show no improvement in mean scores. When individual scores were examined, two participants (B-1 and B-3) reported higher scores, specifically in the domains of 'Experience of being a parent', 'Family life' and 'Child Symptoms'. One explanation could be more severe behaviours related to autism, as reported by higher M-CHAT scores at baseline. Also, lack of engagement in intervention for participant B-3, who missed all three of their weekly scheduled tele-coaching sessions, means that they were unable to receive additional support despite being an identified ‘slow responder’.

Outcomes from the SCC-R also reflect the greatest improvement in mean scores for participants in sequence groups A, E, and F. This was seen across all domains, most notably in ‘imitation/play’ and ‘receptive communication’. Augmenting intervention with synchronous parent coaching sessions, whether weekly or a single rescue session, may provide the support needed to enhance implementation of the strategies learnt. Further, the increase in scores across all sub-domains for participants who received parent-coaching suggests that the synchronous sessions may particularly support parents in utilising everyday teaching moments more holistically by targeting several developmental domains. While participants from sequence groups C and D reported improvement in some domains, with the highest increase in individual scores being reported by participant C-2, the gains were not consistent across domains or participants within sequence groups. Similarly, two out of three participants from sequence group B reported lower scores, despite being allocated to receive weekly synchronous coaching sessions. Other variables, such as parent engagement and severity of child autism related behaviours need to be further investigated to determine possible barriers to intervention.

Outcomes from the behaviour vignette were positive across sequence groups with individual variation amongst participants in the rate of improvement. This variability suggests that acquisition of knowledge may be more related to individual differences amongst parent participants in their ability to receive instruction through modules, rather than as a direct result of parent tele-coaching. One explanation could be that while modules may provide parents with the knowledge of ‘what’ to do, parent-coaching may support parents in transferring this knowledge into practice by learning ‘how’ to do it. The parameters with the most improvement in knowledge, as reported by participants’ answers from the behaviour vignettes, was most notably reflected in parents’ ability to propose environmental modifications and alternative behaviours. However, few participants made gains in their ability to identify un-desired behaviours or environmental factors. This suggests that while parents can make suggestions to enhance the environment and propose alternative desired behaviours, they have a limited understanding of developmentally appropriate skills and behaviours or what barriers may be present in the environment. Considering that the participants in this study were parents of toddlers identified ‘at risk’ of ASD due to certain skill deficits or the presence of certain un-desired behaviours, the absence of a confirmed diagnosis may lead to parents dismissing these concerns.

In terms of parents’ report of their child’s response to intervention, a comparison of outcomes from the status survey conducted at week 3 and post-intervention suggest that the sequence groups that received augmented intervention, whether weekly (B and F) or single (A, and E) parent coaching sessions, reported most improvement in certain targeted behaviours. Although sequence groups C and D had higher mean scores (≥ 80%) at week 3, as a result of which they were identified as ‘responders’, they showed minimal improvement in their scores post-intervention, with three participants scoring exactly 80% (C-1, C-3, and D-5) reporting worsening of target behaviours. One explanation could be that the cut-off score of ≥ 80% might not be an accurate indicator of response to intervention, and that it should perhaps be a higher score. This could allow for more ‘slow responders’ to be flagged for augmented intervention, therefore, potentially improving response to intervention. Further, when considering respond to intervention, it is also important to consider whether ‘responders’ (sequence groups C and D) would have also benefited from augmented intervention to further boost their skills and perhaps incorporating more advanced targets (e.g., generalisation) and reaching a greater potential (Kasari et al, 2018). Overall, it can be said that augmenting the intervention with parent-coaching sessions, whether offered weekly or as a single rescue session, may enhance parents' ability to implement strategies learnt, leading to improved response to intervention and more positive outcomes.

Further, incorporating the status survey as a rapid measure of response to intervention is a successful approach that can be used to identify parent's that need augmented intervention. Considering the heterogeneity of Autism and its impact on response to intervention, being able to rapidly identify slow responders and augmenting intervention with more targeted and personalised support is a key ingredient in providing an adaptive intervention (Kasari et al., 2018). While the status survey is able to measure response to intervention, it is also worth considering whether there are certain predictors of response to intervention that need to be taken into account prior to starting the intervention. For example, understanding whether child age, or language level, is an indication of response to intervention, can allow for a more adaptive intervention whereby decisions can be made for each child individually.

While participants from all sequence groups reported acceptable rates (>80%) of feasibility, acceptability, and appropriateness of the intervention they received, which was evident by low attrition and good attendance rates, some participants did not engage in certain components of their allocated intervention. For example, parents that were offered asynchronous parent coaching through personalised videos based on self-reported areas of challenge, did not all opt in to receive the extra support. Therefore, it is important to consider which sequence of intervention can best encourage active participation and enhance parent engagement. In addition, one participant (B-3) who did not attend any of their scheduled weekly tele-coaching sessions reported the intervention to be acceptable, feasible, and appropriate (total score = 83%). Further analysis of qualitative data may identify possible barriers to engagement in intervention.

There were some challenges in carrying out the current study. During the first leg of the intervention, only one participant opted to receive the asynchronous parent coaching videos during. This limited our ability to compare the response to intervention between participants who received modules only at the start of intervention with participants who received modules in addition to asynchronous parent coaching. Therefore, we were unable to infer which model was the optimal baseline intervention to begin with. Further investigation needs to be done to understand why participants did not choose to receive asynchronous parent coaching videos when offered. The one participant (F-2) who opted to receive the asynchronous parent coaching videos that were personalised to address specific challenges they were facing, showed significant improvement across all measures (SCC-R, Behaviour Vignette, and Status Survey) except for the AFEQ which reflected an increased burden of Autism on family experience. This can be explained by the increased time that was spent engaging in the intervention and implementing the strategies learnt, especially considering the higher level of behaviours associated with Autism reported at baseline from the M-CHAT score – which implies greater severity. While we are unable to infer causation from a single participant, consideration needs to be taken when offering the asynchronous parent coaching videos and whether this could possibly add to parents' burden.

There were some limitations in the current study, that need to be considered in carrying out future research. Firstly, a priori power analysis was not identified due to the decision to carry out a SMART design and analysing data by comparing sub-groups, which would require a larger sample size. Further, the lack of resources available also posed restrictions on our ability to blind the study to increase the validity. These limitations compromise the external validity of the study. Another limitation is that no follow-up was conducted to understand the maintenance of knowledge and skills learned and the long-term impact of the intervention on child behaviours as well as generalisation of skills developed to other caregivers and within different settings. Finally, the most significant limitation to be mentioned is that no objective outcome measures were used as it was outside of the scope of the current research program due to limited resources available, therefore the reported outcomes were based on parent-reported observations. Future studies should include observations of parent-child interactions to measure fidelity of implementation, as well as child observations to validate parent reported outcomes. Considering that the current study is based on coaching parents on providing parent-mediated intervention via telehealth, it may be useful to consider validated observation tools that can be utilised through video-conferencing platforms or by viewing pre-recorded videos.

Carrying out the SMART design to study an intervention program being developed presented as challenging and had limitations that need to be considered when interpreting the findings. However, results from the current study support the feasibility of a brief adaptive intervention of coaching parent mediated NDBI delivered via telehealth for toddlers ‘at risk’ of ASD in the UAE. Preliminary findings from the current study suggest that utilising a rapid measure of response to intervention is a useful tool to identify slow responders, and augmenting intervention with parent-coaching leads to more positive outcomes and improved response to intervention. Further studies exploring intensity of augmentation and addition of supplementary modules based on areas of slow response can contribute to findings from the current study to determine an optimal sequence of adaptive intervention that offers stepped care.

Chapter 5

Parents' Attitude and Engagement in a Brief Adaptive Parent-Mediated NDBI Delivered via Telehealth

The complexity of Autism Spectrum Disorder is reflected in part by its heterogeneity and the different ways in which it may present amongst children across a range of developmental domains (Lord et al., 2020). In addition to the variability in presentation and severity, heterogeneity is also reflected in the diversity observed across countries, cultures, and families. This diversity not only comes from differing beliefs and priorities, but also in access to intervention and community resources (Franz et al., 2017).

Randomized Control Trials (RCT) are the gold standard of evidence in demonstrating efficacy of intervention (Lord et al., 2021). However, demonstrating efficacy of an intervention does not mean that it will be implemented within a community (Cook & Odom, 2013). Utilising alternative approaches that allow the engagement of stakeholders (e.g., family members) in the development and adaptation of interventions should be considered in bridging the research to practice gap (Lord et al., 2021).

While quantitative methodologies have traditionally dominated the research landscape of autism intervention, it may be argued that the heterogeneous nature of ASD necessitates a richer understanding. Mixed method research and qualitative data, emphasising individual experiences, perceptions, and contexts, provides depth and diversity to the autism experience (van Schalkwyk & Dewinter, 2020; de Kort et al., 2022). Moreover, it sheds light on the cultural, social, and individual factors that influence the effectiveness of interventions (Kim & Trainor, 2020). As the field progresses toward more personalised and inclusive strategies, the adoption of qualitative methodologies that supplement quantitative studies becomes more and more necessary. Further, a mixed method study that incorporates qualitative analyses can facilitate greater examination of the social and ecological validity of an intervention, therefore being more culturally responsive (Kim & Trainor, 2022).

In Chapter 4, outcomes from quantitative measures used to examine the impact of a brief adaptive intervention of coaching parent-mediated NDBI delivered via telehealth for toddlers ‘at risk’ of ASD in the UAE were discussed. The outcomes demonstrated the feasibility of an adaptive approach to intervention within a representative sample, that may better address the variability and individual differences between children and their family context. Although parents that were randomly allocated into sequence groups that received augmented intervention had more positive outcomes overall, there was a reported variability in outcomes amongst individual participants, within and across sequence groups. An in-depth understanding of participants’ perceptions and experiences may provide insight into whether there are other factors, or mediators, that could influence the effectiveness of the intervention provided. This could potentially allow for a more ‘tailored’ and personalised approach in deciding what intervention to offer at baseline, what supplemental interventions should be offered, when to augment and at what intensity, in order to optimise the adaptive intervention and provide what may be considered personalised stepped care.

An in-depth understanding of factors that influence participant adherence and engagement in intervention is especially important when delivering interventions through telehealth. While tele-interventions potentially improve access to care, their effectiveness may be limited by low levels of participant adherence and engagement (Clough et al., 2019). A useful, and widely used, framework that facilitates the understanding of participant adherence to innovative interventions, and guide its development, is the Theory of Planned Behaviour (TPB) (Mathieson, 1991). This theory, developed by Ajzen (1991), asserts that behavioural intentions, which is an individual’s willingness to engage in a specific behaviour, are the immediate antecedents to behaviours. According to TPB, there are three factors that influence behavioural intentions, which are: Behavioural

Attitudes; Subjective Norms; and Perceived Behavioural Control (PBC) (Ajzen, 1991). Behavioural attitude refers to whether the individual perceives or believes the behaviour positively or negatively (e.g., belief that the intervention is helpful/unhelpful), subjective norms refers to whether the individual perceives the behaviour to be appropriate for them based on others' judgments and social pressures (e.g., perception that their significant other would/would no support them); while PBC refers to whether the individual perceives that they have the self-efficacy or capacity to do the behaviour (e.g., perception that they are/are not in control over whether they do the intervention) (Ajzen, 1991).

The current chapter provides an in-depth thematic analysis of the qualitative data collected from 20 participants following completion of a six-week intervention cycle (described in Chapter 4). The primary aim was to investigate parents' perception of the intervention to understand its social validity within the context of the UAE. The secondary aim was to identify possible facilitators or barriers to intervention. Emerging themes derived from the analysis will also be discussed in the context of the variability in some of the outcomes within sequence groups, as reported in the previous chapter.

Method

Participants and Setting

Participants in the current study were recruited as part of an investigation of a brief adaptive parent mediated NDBI delivered through telehealth. The investigative study followed a Sequential Multiple Assignment Randomized Trial (SMART) design. A total of 20 participants completed the six-week intervention cycle, which included different sequences of interventions adapted based on participant response mid-intervention. Participant characteristics and setting was previously described in Chapter 4 and summarised in Table 5.1 below.

Table 5.1

Summary of the demographic data of participants from sequence groups A, B, C, D, E, and F.

	Age (years)	Education level	Number of children	Employment status
A1	30-39	High School	3	Unemployed
A2	30-39	Undergraduate	2	Unemployed
B1	20-29	High School	2	Unemployed
B2	20-29	Undergraduate	2	Unemployed
B3	30-39	Graduate	1	Employed (Full-Time)
C1	30-39	Graduate	≥ 4	Unemployed
C2	30-39	Some College	2	Unemployed
C3	30-39	High School	≥ 4	Unemployed
C4	30-39	High School	3	Employed (Part-Time)
D1	30-39	Undergraduate	2	Employed (Part-Time)
D2	30-39	Undergraduate	2	Employed (Part-Time)
D3	40-49	High School	≥ 4	Employed (Full-Time)
D4	30-39	Undergraduate	2	Employed (Part-Time)
D5	30-39	Graduate	≥ 4	Unemployed
E1	30-39	Graduate	2	Unemployed
E2	30-39	Undergraduate	≥ 4	Employed (Part-Time)
E3	30-39	Undergraduate	2	Employed (Part-Time)
F1	30-39	Undergraduate	≥ 4	Unemployed
F2	30-39	Graduate	2	Employed (Part-Time)
F3	30-39	High School	≥ 4	Employed (Part-Time)

Data Collection and Analysis

Interview data was the primary source of qualitative data for the current study. Given the complexity of the study design, and lack of previous studies investigating an adaptive parent-mediated intervention delivered via telehealth in the UAE, it was decided that a bespoke semi-structured questionnaire would better capture parents' attitude towards, and engagement in, different components of the intervention, while considering the cultural context of the UAE. All participants completed the Attitude and Engagement in Intervention Questionnaire (AEIQ). The AEIQ is a 25-item semi structured questionnaire which was developed by the primary investigator to measure parents' engagement in different components of the intervention. The questionnaire included eight 'open ended' components embedded within some items, as well as items that were multiple choice or 'yes/no' questions. Translation of the AEIQ into Arabic was conducted by the primary investigator.

The semi-structured interviews were conducted by phone, following the 6-week intervention, with the support of the primary investigator. Most interviews with participants were 30 minutes in duration. Data were gathered on participants' general views on different components/domains of the intervention, including: General Structure of the Program; Video modules; Coaching sessions; and their Attitudes towards the intervention and perceived barriers. Qualitative data gathered from the AEIQ were transcribed and coded by the primary investigator. Table 5.2 below provides an overview of the AEIQ items and their corresponding domains.

Table 5.2

Overview of the Attitude and Engagement in Intervention Questionnaire (AEIQ) and corresponding domains.

Domain	**Number of Questions**	**Number of Open-Ended Component**	**Description**
General Structure	4	1	Questions regarding parents' opinions on the duration of the intervention cycle, frequency of sessions, and parent participation in different components.
Video Modules	3	1	Questions regarding the quality of the video presentations and content, and suggested topics to be covered
Coaching Sessions	6	2	Questions regarding the adequacy of the frequency and duration of coaching sessions, and explanations for any missed sessions.
Attitudes/Barriers	12	4	Questions regarding the usefulness of the intervention program in relations to a confirmed ASD diagnosis; beliefs on ability of parents to implement intervention vs. processionals; generalisation of learnt strategies; and social validity of intervention goals.

Field notes collected by the primary investigator from interactions with the participants during the coaching sessions were also included in the current study as a secondary source of qualitative data. These were in the form of unstructured comments shared by parents outside of the structure of the coaching session, which were transcribed and coded by the primary investigator and used as supplemental qualitative data.

Considering the complexity of the current intervention study, a thematic analysis approach was utilised as a well-structured method that is useful for examining perspectives from different participants, while allowing the flexibility to be modified to different study designs and provide a rich and complex account of the data (Nowell et al., 2017). Data emerging directly from the interviews were inductively analysed using a well-established approach for thematic analysis identified by Braun and Clarke (2006), which includes: Familiarisation with the data; generating codes and refining the data into meaningful segments/themes; reviewing and defining themes; and final analysis. Emerging themes were interpreted within the context of the sequence of intervention received by participants, cognisant of the Theory of Planned Behaviour.

Results

The analysis resulted in the identification of seven themes which will be divided into two sections: 1) characteristics of the intervention program; and 2) perceptions and attitude towards intervention. Regarding the structure and content of intervention, two broad themes were identified, which are, *valued aspects of the intervention*, and *limitations in delivery of intervention*. While five themes emerged regarding perceptions and attitude towards intervention, including: *parents' perception of their role in intervention*; *time investment*;

significance of a therapeutic alliance; *understanding of child’s needs*; and *generalisability*. These themes included further sub-themes that emerged from the data, which will be presented along with quotes, some of which were translated from Arabic. Table 5.3 provides an overview of emerging themes and subthemes regarding the two sections.

Table 5.3

Overview of Themes and Sub-themes regarding Characteristics of the Intervention program and Perceptions and Attitude towards Intervention.

Section	**Theme**	**Sub-theme**
Characteristics of the Intervention Program	Valued Aspects of Intervention	Accessibility and Flexibility
		Clarity and relevance of content
		Qualities of coaching sessions
	Limitations in Delivery of Intervention	Need for supplementary content
		Lack of hands-on demonstration
Perceptions and Attitude Towards Intervention	Parents' Perception of their Role in Intervention	Feeling of Empowerment
		Professionals as primary interventionist
	Time-investment	Willingness to implement
		Demands of daily life
	Significance of a Therapeutic Alliance	Sense of support
		Worries about the future
	Understanding of Child's Needs	Acceptance and hopefulness for the future
		Significance of a confirmed diagnosis
	Generalisability	Application in daily life
		Lack of motivation from other stakeholders

Characteristics of the Intervention Program

Valued Aspects of Intervention

During interviews, parents expressed their views around certain aspects of the intervention program which they found to be positive. 'Valued aspects of the intervention' was considered a theme, which could be further divided into sub-themes, including accessibility and flexibility; clarity and relevance of content, and qualities of coaching sessions.

Accessibility and flexibility were a clear sub-theme identified in the analysis. A key component in the intervention program is that parents receive web links to access the video modules and tele-coaching sessions. These links were sent to individual parent participants through private messages on 'WhatsApp' mobile phone application. The messaging application was also utilised by parents to communicate any issues they were facing with the videos, and to schedule/re-scheduling coaching sessions. Parents who were offered coaching sessions found "it was helpful to be able to message [the clinician] when I can't make it to our session or if I was running late" (F-1). Most parents found that receiving these communications directly to their phone, on an application they frequently use during their day, made it easier for them to access the intervention and served as a reminder for them to complete the tasks.

"I don't always remember to check my emails because I don't work. But I am always on WhatsApp, so it was easy for me to just check the messages when I get a notification and click the link on my phone to watch the video at work or anywhere". (A-2)

Another way parents described the intervention to be accessible was due to being brief with no demand for any specific equipment or toys, most parents "did not need to buy anything, the normal things I had at home were enough" (D-4). One parent said, “I don’t think any parent will not have 20 minutes a week to watch a video that can help their child…. I am a working mother and I used to watch the video during my lunch break, and for the sessions it can be done at a time that suits me” (F-2).

Parents also valued the flexibility in the delivery of the intervention, as they “did not need to watch the video at a certain time” (C-2). Most parents expressed their preference to watch the video modules at their own pace and in their chosen time. One parent said,

“I was sick in week 5 so I couldn't watch the video that week or attend the session, so I watched the video the next week with week 6 and we did a longer online session, and I didn’t feel like I missed anything” (F-1).

Clarity and relevance of content was another sub-theme that emerged from the data. The video modules that were shared with parents consistently followed a specific structure whereby the topic or skill would be presented, followed by a comparison of how that specific milestone presents in typical development compared with children with social communication deficits, after which there would be a description of steps to be followed in order to implement the teaching strategies with examples. Most parents described the videos to be presented clearly and that the “topics all made sense” (C-1). Some parents described the part of the video where the ‘steps’ were presented was “very useful and easy to follow” (D-3) with one parent sharing that she would “take screen shots of the ‘steps’ slide to look back on during the week” (F-1). Parents expressed their various views and preferences for different parts of the videos that were most relevant to them. One parent said,

“For me, the start of each video when you talk about the topic or skill of the week and how this happens in normal development compared to children with autism was the most important part... It always opened my eyes and made me realise the things [child name] did not do yet and made the whole topic make sense" (A-1).

Another aspect that parents valued in the intervention program were certain *Qualities of the coaching sessions.* Coaching sessions were typically scheduled with parents at the end of the week and were structured to allow time to reflect on the previous week's topic, challenges faced in implementation, and motivational interviewing to coach parents in implementing the teaching strategies more effectively. Most parents who received coaching sessions described them as being an enjoyable part of the intervention program where they had the chance to "ask questions freely and talk about my child's challenges specifically" (B-1). Parents also expressed that having the videos sent a few days before the sessions was ideal in allowing some time to attempt the strategies discussed in the videos. One parent said,

"Having the video at the beginning of the week and then meeting 1 on 1 at the end of the week was perfect because we have a chance to rectify what we got wrong and [the clinician] gave suggestions and examples on how to implement the challenging parts" (F-3).

Limitations in delivery of Intervention

During the interviews, some parents described certain aspects of the intervention to be limited and expressed their wish for additional features to be included in the intervention program. This was considered a theme that could be divided into three sub-themes which were: need for supplementary content; lack of hands-on demonstrations; and frequency of coaching sessions.

Most parents expressed the *Need for supplementary content* to be included within the program. The content of the program and topics presented were based on the ESDM parent manual (see Chapter 2) and focused on behaviours or developmental milestones typically targeted within NDBIs. While most parents generally described the topics as being relevant and useful, there were certain gaps that were identified by some parents who want "more about behaviour" (B-2) (with the term 'behaviour' pertaining to problematic or concerning child behaviours) and "more lessons on how to help the child speak" (B-1). While the intervention program covered the basics of understanding behaviour and promoting communication within the content, some parents expressed their desire for additional material that could supplement their learning. One parent said,

"I want to know more about what to do when new behaviours appear and what to do when my child gets angry… that is my biggest problem with [child name]" (D-1).

Lack of hands-on demonstrations was another limitation identified by parents. Many parents expressed their interest in more "practical demonstrations" (C-4) of how to implement the strategies taught. Some parents wished to include "more real-life examples and videos to teach us how to use the tools provided" (F-2). Many parents expressed their preference to "have more coaching sessions" in order to have an opportunity to observe demonstrations of how to implement the strategies covered. One parent said, "I wish I could have had more than one coaching session a week. I could talk about more real examples of situations I face with [child name] and [clinician] can show me how to deal with it" (F-3).

Perceptions and Attitude towards Intervention

During interviews and interactions with the primary investigator throughout the six-week intervention cycle, parents communicated their thoughts and perspectives on participating in the parent-mediated intervention program. There were five distinct themes that emerged from the data, with each theme being further divided into sub-themes.

Parents' Perception of their Role in Intervention

Many parents described a *Feeling of empowerment* they experienced as they began to gain knowledge and embrace their role as mediators of intervention. Some parents attributed this feeling of empowerment to having a set of targets each week, "Having a plan has given me the courage to hold myself together and continue trying until I see some improvement in my child" (D-3). One parent expressed that "when [the clinician] started explaining the 'big 5' daily activities it made sense, of course the parent has to do this because we are the ones there during bath time and bedtime and all these activities" (C-3). Another parent attributed a sense of empowerment from acknowledging parents' wellbeing as a facilitator in intervention, saying, "I was very touched in the last session when the focus was on mother well-being and taking care of myself to take care of my child" (A-1). Parents who received coaching sessions specifically expressed their beliefs of knowing "how to make small changes in the day to help my child" (A-1) which gave them the confidence that they are "capable of helping" (A-2). One parent said,

"The first 3 weeks were hard because the results were not showing directly, and I thought I was doing something wrong. But after our sessions I began to feel that I can do it because I can see small changes every day" (F-2).

Some parents expressed the limitations of parents providing intervention and viewed *Professionals as primary interventionists.* For some parents this was attributed to not having "enough experience" (B-2) and not being "an expert in this field" (D-5). Although most participants viewed the parent to be "capable of implementing the intervention strategies", many believed that "this intervention should be implemented by a trained professional". One parent said,

"I'm not a professional…my child needs someone who is expert and knows how to make him talk or be the same as other children" (B-3).

Time-investment

Some parents expressed their *Willingness to implement* the strategies that were taught throughout the intervention. This was described in the context of taking advantage of the opportunity to learn how to help their child and a sense of gratitude, “a lot of parents don’t have this chance and if someone is taking the time to help me then I need to take the time also to help my child” (F-2). Many parents acknowledged that it was difficult to find the time to complete the assigned tasks and practice the strategies with their children but were motivated by positive outcomes. One parent said, “It's hard of course when I am working all day and come back tired, and I have other children but when I see my son changing and improving then I spend more time…it’s worth the effort” (A-1).

Many parents described the *Demands of daily life* as being the biggest obstacle for not watching the videos on time, not practicing the strategies, and missing the scheduled coaching sessions. The most frequently mentioned factor was that they “have other children” (C-1) and they “got busy at home” (B-3). Parents frequently referred to the need to allocate time to exclusively ‘focus’ on activities with their child. One parent described her challenges in finding time by saying,

> “I work during the day and when I come home, I have to make sure everyone eats and does their homework or go to their activities on time… every day I say I will make the time to focus with [child name] but sometimes things just come up" (C-4).

Significance of a Therapeutic Alliance

Most parents who received coaching sessions as part of their intervention, described a *Sense of support* during interactions with the clinician, which made some feel “not alone” (F-2) and “very comforted by [the clinician]’s words” (F-3). Some parents expressed feeling support when they were “always asked if the activity works for me or fits in my life" (F-1). One parent described feeling support by the clinician's acknowledgment and validation of their feelings of stress,

"The sessions were educational to me. There was support and understanding to the pressure and the stress I was going through as a mother and when I could not do something, [the clinician] did not judge me or put pressure, [the clinician] would just try to find a way to make it work for me" (A-1).

Simultaneously, parents also expressed their *Worries about the future.* Specifically, they described feelings of uncertainty about their child's future, or being "lost" once the intervention is over. This was expressed in the context of their situation prior to the intervention, "I'm so used to the Monday videos and Thursday sessions. Now I will go back to just waiting for our appointment" (E-2). One parent described her concern around the lack of support for parents awaiting diagnostic assessments by saying, "There is no one to help us. We have been waiting for our appointment for a very long time and wasting time and we don't know who is the right person to help our child" (B-1).

Understanding of Child's Needs

Acceptance and hopefulness for the future was expressed by many parents. They described having a better understanding of their child's strengths and weaknesses as a result of the knowledge gained from the intervention. This was paired with a sense of hopefulness for the future, "[child name] is special and I love him how he is, as long as I know how to help him then everything will be ok" (C-3). One parent said, "The first video is an eye opening and comforting video. It gave me hope that my child is different and there are some small changes that I could do that will change his life" (A-1).

Some parents emphasised the *Significance of a confirmed diagnosis.* This was expressed through questioning the relevance of the content for a child not diagnosed with

ASD, “In the videos it is all for children who have autism, but my son does not have autism we are still waiting for his assessment” (C-2). Although the content of the intervention consistently described the strategies as useful for children with ‘challenges in social communication and interaction’, rather than explicitly for children with ‘Autism’, some parents continued to express confirmation that their child “does not have Autism”. All participating parents had an awareness that their child had been referred for an Autism diagnostic evaluation due to concerns around social communication and interaction, however, few perceived the strategies to be irrelevant, highlighting the significance of a confirmed diagnosis. One parent said, “You should first see my child and assess him first, how do you know what he needs… I’m not sure, I prefer to assess my child first and if he has Autism then I can get him the help” (B-3).

Generalisability

Many parents expressed that they were able to generalise the strategies learnt in different environments, as well as transfer the knowledge to others, due to its ease of *Application in daily life*. Parents described the activities to be naturally occurring, which contributed to its potential for generalisation. One parent said, “My child was able to use some skills everywhere because it is relevant to our lifestyle and routines. She began to play with her grandmother and do the same songs we practised when we visit them” (F-2). Some parents expressed the necessity for transferring the knowledge to other individuals in the household, mostly nannies or other caregivers, as their children spent a greater portion of their day with them. One mother said,

> “Every week I tried to explain to our nanny and my husband about the topic and what to do and they started to do the same. Especially my nanny because she is with him a lot in feeding time and dressing up” (D-1).

Some parents communicated a *Lack of motivation from other stakeholders* or family members which presented a barrier for generalisation. Various reasons were described to contribute to this lack of motivation. One parent described her husband's denial or disbelief that their child had concerns around social communication and interaction, she said, "My husband doesn't think there is anything wrong with our son, so he thinks we don't need to do assessment or therapy" (B-1). Some parents perceived other caregivers to be not as motivated as they were because they are "not willing to put the effort" (D-3). One parent said, "Sometimes my nanny will still give [child name] everything or feed [child name] … I think because it's easier for her" (C-1).

Discussion

The purpose of the present study was to explore the social validity of a six-week parent mediated NDBI delivered via telehealth to parents of toddlers 'at risk' of Autism in the UAE. To the best of our knowledge, this qualitative study is the first to investigate the perceptions and attitudes of parents in the UAE to such an intervention program, which enabled us to identify possible facilitators and barriers to this modality of delivery. Themes and sub-themes emerging from the qualitative data were related to both parents' opinions on the characteristics of the intervention program, as well as their perceptions and attitudes towards intervention. Overall, the delivered intervention was perceived by parents as helpful, empowering, and applicable, while also having practical challenges in implementation and limitations in its delivery. The themes will be discussed in the context of barriers and facilitators of intervention and the implications for clinical practice.

Perceived Strengths and Limitations of the Intervention Program

Parents conveyed their appreciation of the intervention program, including its duration, ease of access, and flexible nature. They also valued aspects from the program's different components including the clarity and content of the video modules and how the coaching sessions were structured. Despite these positive attributes, parents identified the need for ‘more’ knowledge and practical demonstrations. This suggests that while parents were understanding the content and strategies, they were facing challenges in its practical implementation, which may explain the request for more frequent coaching sessions and more hands-on demonstrations or modelling. An effective evidence-based strategy of coaching and training parents to provide intervention to their children with ASD, is Behaviour Skills Training (BST) (Schaefer & Andzik, 2021). BST has been delivered via telehealth in parent-mediated interventions for children with ASD (Werner Juarez, 2021; Boutain, Sheldon & Sherman, 2020) and involves instruction, modelling, rehearsal, and feedback. Components of BST may be incorporated into future coaching sessions to enhance its effectiveness. While obtaining recordings or conducting tele-observations of parent-child interactions was outside the scope of the current study, incorporating an observation component into the delivered intervention program may provide additional support and more robust coaching sessions. The effectiveness of video-feedback in parent mediated interventions for children with ASD was previously demonstrated, showing improved competence and parent-child relationship (Poslawsky et al., 2014). However, discussing video-recordings may bring out feelings of insecurity and vulnerability with some parents and be considered a possible barrier (de Korte et al., 2022). This may especially be the case within the cultural context of the UAE, as some parents were more hesitant to turn-on the camera during tele-coaching sessions. Parents also specifically identified the need for additional material to supplement their knowledge and understanding of behaviour management and communication. While these topics were covered within the planned intervention, including the option for additional modules that cover these topics in more detail may provide a more in-depth understanding, especially for parents that experience their children engaging in challenging behaviours.

Identified Facilitators and Barriers in Implementation

There were several factors that were identified as facilitators in the implementation of the intervention. These include parents' feelings of empowerment, the willingness to invest time, the therapeutic relationship between parent and clinician, acceptance and understanding of the child's needs, and applicability in daily life.

It is important to consider how some of these facilitating factors relate to each other in order to better understand their impact on parental engagement in intervention. One concept to consider is the therapeutic relational connection, which can positively impact intervention outcomes such as adherence (Duffy et al., 2023). Duffy et al. (2023) suggest that it is important that the intervention provider is trained in interpersonal communication skills in order to address challenges that are specific to utilising telehealth, including; the lack of human contact; distance creating mistrust; and the inability to rely on nonverbal communication, in order to foster a positive therapeutic relational connection. A strong therapeutic alliance that fosters feelings of support and empathy may lead to parents feeling more empowered (Leadbitter et al., 2020). In turn, parents that are empowered, may be more willing to invest time into implementing the strategies. This is in line with the theory of planned behaviour's definition of perceived behavioural control as a factor that influences behaviour intention (Ajzen, 1991), and parents 'willingness' to engage in implementation of the intervention. Further, parents understanding of their child's needs may also lead to them feeling more empowered to help.

Another identified facilitator was the applicability of the intervention and ease of transfer of knowledge across settings and individuals. Within the cultural context of the

UAE, families often share a household with extended family members (e.g., grandparents or other caregivers). In addition, families often also rely on help provided by live-in nannies or caregivers that are also members of the household. Therefore, the ‘transferability’ of the skills learnt is especially important in promoting generalisation and facilitating engagement in the intervention.

In regard to barriers, parents’ acceptance of their child’s challenges and their understanding of the importance of their role as their child’s primary interventionist were major factors that impacted parent engagement in the intervention. Edwards et al. (2018) described a journey of therapeutic change that parents of children with ASD go through which influences their decisions on implementation of intervention. This transformation from ‘parent to expert’ begins with initial doubts over diagnosis and high expectations and evolves to an understanding and acceptance of their child’s needs, ending with developing the expertise in their child (Edwards et al., 2018). Understanding where parents are in the journey of therapeutic change may provide insight on their potential for engagement in intervention, allowing for adjustments to be made to accommodate each parent and their emotional starting point (Leadbitter et al., 2020). In addition, experiencing positive outcomes from intervention may support some parents to get past initial feelings of resistance and insecurity (de Korte et al., 2022). This was the case for one parent in the current study who described experiencing difficulties at the beginning of the intervention and feeling insecure about her ability to implement the strategies, which changed after observing improvements in her child.

Another factor to consider is that within the cultural context of the UAE, parents often subscribe to a medical model of disability, believing that deficits are only validated with a medical diagnosis, and that professionals are responsible for treatment. In a study done by Hussein et al. (2011), parents’ from Saudi Arabia reported their treatment preference for their child with ASD to be either through a combination of pharmaceutical treatment and behavioural therapy, or pharmaceutical therapy alone, with no parents reporting a preference for behavioural therapy alone. This is an underlying barrier that can explain some parents' emphasis on 'not having a diagnosis yet', implying that they did not need to intervene yet. Further, when other family members or stakeholders believe this, it can also impact parent engagement in intervention, as well as generalisation of gains. This is also supported by the concept of subjective norms as a factor that influences behaviour intentions in the theory of planned behaviour (Ajzen, 1991).

Another identified barrier, and perhaps the most significant one, is parental demands of daily life creating an obstacle in dedicating time to watch the video modules, attend sessions, and implement the strategies learnt. Studies that also highlighted these challenges emphasise the importance of flexibility, ease of access, and practicality to improve engagement in effective interventions (Carr & Lord, 2016; Leadbitter et al., 2020). Considering that steps were taken to ensure flexibility in delivery of intervention, and that all components of the intervention could be accessed easily and practically, it is worth investigating whether parents falsely attributed their lack of engagement in some parts of the intervention to being busy despite there being an underlying issue of motivation or 'buy in'.

There are some limitations to the current study that need to be considered. First, the primary investigator was the same person delivering the intervention and conducting the interviews. This may have influenced parents' feelings of being able to give candid views, both positive and negative. We attempted to mitigate this by conducting the interviews after the intervention was completed, and by reassuring parents that their responses would not be identifiable and that their honest feedback would be valuable in improving future intervention cycles. Another limitation is that there were no interviews conducted pre-intervention or during intervention. This means there was no insight to parents' attitudes towards intervention prior to starting the program in order to observe any possible changes, nor were there reflections on the parents' experiences during the intervention period to understand their therapeutic journey and possible challenges. Further, it would also be insightful to conduct semi-structured interviews with other family members and caregivers to understand the impact of intervention on them. It may be valuable also to consider the inclusion of a comparison group of parents who remain on a waitlist without accessing any supports which reflects typical experience in the UAE and other countries. Interviewing these parents in parallel to an intervention group could provide useful information on support needs. The current study was limited in this way, given the resources available to the researcher and the constraints within the hospital setting.

It may be considered that the current findings have important clinical implications and reinforce the importance of adaptability in planning parent-mediated interventions. The facilitators and barriers discussed can be a useful and informative place to start when looking to identify potential mediators in designing adaptive interventions. Pre-intervention interviews or questionnaires designed to understand parents' expectations, concerns, and perceptions, may allow interventionists to design an adaptive intervention with targeted supplementary materials and modules to address specific needs. Further, it will facilitate a better understanding of where parents are on their journey of therapeutic change, to identify parents that are in the early stages who may require pre-intervention modules that target their understanding of social communication deficits, and the role of parents as primary interventionists.

This qualitative data analysis has provided important insights into parents' perceptions of a parent mediated NDBI delivered via telehealth in the UAE. It also provides a deeper understanding of parents’ experiences of facilitators and barriers which can serve as a resource for future research.

Chapter 6

Effective Implementation of a Parent-Mediated NDBI delivered via Telehealth in the UAE

In chapters 4 and 5, results from an adaptive parent-mediated NDBI delivered via telehealth were presented and discussed, supplemented by an in-depth exploration of parents' attitudes and engagement in the intervention. The outcomes discussed were considered promising and demonstrate feasibility and acceptability of the adaptive intervention, improvement in parent knowledge, and improvement in parent-reported child outcomes. An important in depth understanding of parents' perceptions of facilitators and barriers was also gained. The mixed-methods approach undertaken facilitated a comprehensive investigation of the effectiveness of the adaptive intervention. However, in addition to developing, refining and personalising effective intervention, planning for effective implementation is necessary to bridge the research to practice gap.

An important factor in ensuring effective implementation, is the use of implementation science in planning the intervention from the beginning (Schlebusch et al., 2020). The elements and phases of the current research program have been deeply rooted in implementation science theory. Designing a contextually fit parent-mediated NDBI delivered via telehealth began with, an exploration of the intervention through a pilot study; followed by preparation through the development and adaptation of intervention content and translation of outcome measures; the implementation of an adaptive intervention; and finally, identification of potential barriers and facilitators within our local context. The current chapter will discuss the development and tailoring of implementation strategies that may address the barriers and enhance the facilitators identified as the final stage of our research program. The highlighted implementation strategies will also be considered within the context of the recent recommendations for 'stepped care/personalised health model' for autism intervention proposed in the Lancet Commission on the Future of Care and Clinical Research in Autism (Lord et al., 2021).

Effective Implementation of NDBIs in a Resource Limited Context

To ensure greater benefit for children and families, an important and pivotal component to consider, which may determine the success or failure of an intervention, is the implementation context (Schlebusch et al., 2020). When planning implementation of NDBIs in resource limited contexts, as is the case in the UAE, Schlebusch et al. (2020) argue that there are key considerations that need to be understood, including: a) the natural context in which intervention occurs; b) the developmental trajectories/targets to be prioritised; c) the behavioural targets to be taught within specific cultures and contexts; and d) the way in which effectiveness of intervention is measured in the absence of contextually validated tools.

Considering that most studies investigating NDBIs have been conducted in non-representative populations, adaptation of certain elements of NDBI programs need to be carried out in order to enhance its alignment with local contexts and settings (Schlebusch et al., 2020), which in turn may increase the likelihood of the intervention being adopted (Greenhalgh et al., 2004). Further, evidence suggest that effectiveness of intervention programs can be improved through cultural adaptations (Chambers & Norton, 2016).

When considering the natural context in which intervention occurs, some key factors that were identified by South African caregivers to be important in ASD intervention include culture, language, cost of treatment, and stigma (Guler et al., 2018). Within the context of our study, sessions were conducted in the Arabic language (or language of choice), materials translated, treatment was free of cost, and sensitivity to a diagnosis of ASD was considered when creating the material used in intervention (e.g., referring to challenges as ‘social communication challenges’ rather than ‘Autism’). However, since NDBI strategies are embedded into daily routines, one factor which needs to be considered in future implementation of the intervention program is the context of the local family life in UAE, and who interacts most with the child on a daily basis. For some families, other caregivers (e.g., nannies or grandparents) may be more suited to receive the intervention. Another factor to consider is the sensitivity of the training methods to the cultural context of the UAE. During our intervention study, many parents hesitated to switch on the ‘video camera’ during coaching sessions. This may be due to some mothers’ need to comply with traditional or religious dress codes, and not being sure of who will be present in the room while the clinician is conducting the session. As such, being ‘unprepared’, or appearing on camera without a veil (which is a requirement for women practising Islam), may be a barrier to some mothers. Therefore, this needs to be considered when requesting parents to switch the ‘video camera’ on to maximise engagement.

Regarding prioritising developmental or behavioural targets within the context of the UAE, there are no studies to our knowledge that investigate context specific developmental trajectories or socially valid behavioural targets. This is an area for further research, however, qualitative data from our study suggest that parents valued more in-depth knowledge of management of difficult behaviours and verbal communication.

When considering the measurement of effectiveness of intervention, steps were taken to back-translate outcome measures relevant to the implementation of parent-mediated NDBI, as discussed in Chapter 2. This facilitated the use of a hybrid approach that incorporated both quantitative and qualitative measures of both intervention outcomes, as well as implementation outcomes, which allowed the identification of facilitators and barriers in the implementation of our intervention. Future implementation should focus on including fidelity outcome measures in evaluating implementation of the intervention. Fidelity of procedural implementation delivery is defined as the extent to which an implementation strategy is carried out as it was designed. Pragmatic solutions exist for researchers to make immediate improvements that involve the staged use of fidelity measurement tools, the use of mixed methods or innovative data collection and analysis techniques,

Mapping Implementation Strategies

The goal of implementation science is to narrow the research to practice gap and improve intervention outcomes through the identification of determinants that influence implementation and the systemic utilisation of implementation strategies that address these determinants within a specific context (Sridhar et al., 2023). Indeed, a priority in implementation science is to "enhance methods for designing and tailoring implementation strategies" (Powell et al., 2019 p. 1). Implementation strategies ultimately aim to increase the adoption and initial uptake of an intervention within a novel setting, as well as sustaining its utilisation (Powell et al., 2019). These strategies are believed to have a positive impact on implementation outcomes, service outcomes, as well as individual outcomes (Proctor et al., 2011).

Implementation strategy mapping is a pre-implementation approach of identifying determinants and methodically select and tailor implementation strategies within different contexts and matching these to identified determinants (barriers and facilitators) (Sridhar et al., 2023). Although there are many frameworks and theories that describe how to methodically tailor and select implementation strategies, there remains a need to critically evaluate these methods (Powell et al., 2019). Further, in a scoping review done by Sridhar et al. (2023), the authors reported a lack of clarity on how to best identify whether a particular theory or framework is more appropriate in implementation strategy mapping within a specific context. While there is consensus that selecting and tailoring implementation strategies through systematically addressing barriers and enhancing facilitators of intervention, within child mental health service delivery settings, may improve implementation and clinical outcomes, there is a lack of clarity on how to best identify whether a particular framework is more appropriate to use in implementation strategy mapping, within a specific context (Sridhar et al., 2023).

In a scoping review carried out by Albers et al. (2017), it is argued that while relying on a solid implementation framework, rather than researchers' opinions is beneficial in the implementation process within child and family service sectors, most of these frameworks were developed for a specific context and purpose, and their alignment with other cultural contexts is limited. There are common factors, or core elements, included in implementation frameworks, which if used flexibly and combined within a 'modular' approach, can enable the application of effective elements for specific purposes in different contexts (Albers et al., 2017). In the implementation planning stage of our research program, utilising an implementation framework may guide the development and tailoring of implementation strategies and support the process of matching these strategies with identified barriers and facilitators.

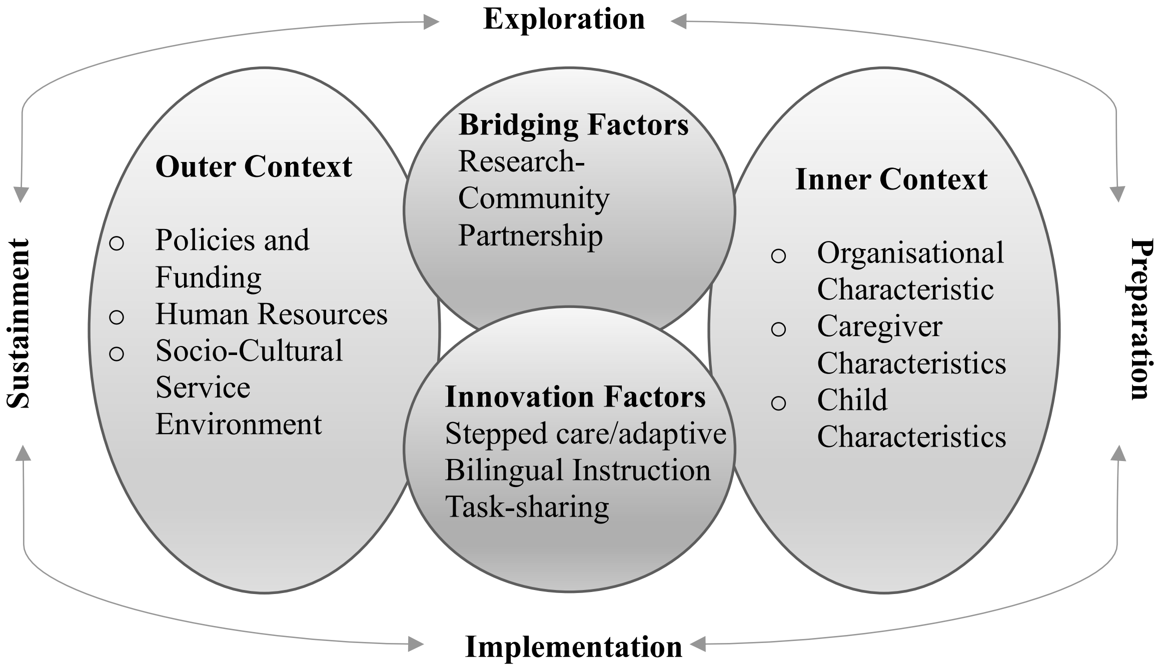
In selecting a suitable implementation framework, one of the important aspects to consider is the setting and type of intervention it was originally designed for (Moullin et al., 2020). Exploration, Preparation, Implementation, Sustainment (EPIS) is a framework used to develop and adapt evidence-based practices for young people with ASD in mental health settings (Dickson et al., 2020; Stadnick et al., 2019; Stahmer et al., 2019). The framework divides the implementation process into four phases (exploration, preparation, implementation, and sustainment) and emphasises contextual factors (inner and outer), as well as implementation factors (bridging and innovation), within each phase (Aarons et al., 2010). The outer context specifies external factors (e.g., service environment and client characteristics), while the inner context specifies internal factors (e.g., organisation, provider characteristics). Bridging factors are related to linking inner and outer contexts (e.g., research-community partnerships, stakeholder involvement), while innovation factors relate to elements that increase fit between the intervention and the context in which it is being implemented. Given its alignment with the focus of our current research program, the EPIS framework will be applied in the development of implementation strategies that address barriers and enhance facilitators identified in the current study.

Implementation Barriers and Facilitators

Understanding the contextual factors that influence each phase of implementation allows the proactive targeting of implementation barriers and facilitators within community early intervention settings, in turn, maximising successful delivery of intervention. Outer and inner contextual factors that may impact implementation will be discussed, in addition to innovation and bridging factors that interplay with these contextual issues. Figure 6.1 provides a conceptualisation of the EPIS implementation framework, adapted from Aarons et al. (2010), relevant to the implementation of a parent mediated NDBI delivered via telehealth in the UAE.

Figure 6.1

Conceptualisation of the EPIS implementation framework (adapted from Aarons et al. 2010) of a parent mediated NDBI delivered via telehealth in the UAE.



Outer Contexts

Policies and Funding. The provision of early intervention for children with ASD is determined largely by policy and funding. In some high-income countries, children under the age of three presenting with early signs of ASD are eligible for publicly funded intervention services, while in many middle- to low-income countries, there is limited access to publicly funded early intervention (Stahmer et al., 2019). In the UAE, the 'National Autism Policy' states its aim is "improving the health and well-being of people with autism spectrum disorder and to supporting caregivers" under the premise of ensuring high quality diagnostic services, improved access to healthcare, expanding human resources, promoting inclusion in education, and community awareness and empowerment (UAE Ministry of Community Development, 2023). However, there is a gap between policy and practice, which has contributed to long 'waitlists' for diagnostic assessments, and a delay in starting early intervention. In addition, public funding of early intervention services in the UAE remains limited for children diagnosed with ASD, and non-existent for younger children below the age of 3 years who may be diagnosed with or ‘at risk’ of ASD.

Human Resources. The scarcity of human resources or trained professionals that are experienced in implementing early interventions in the UAE is another outer context factor that needs to be considered. This is especially the case in less-urbanised emirates, as ASD specialists trained in the delivery of evidence-based interventions are typically based in more urban areas. Currently, there are no federal policies that license ABA service providers in the UAE (Kelly et al., 2016). The availability of licensed professionals is further exacerbated by the lack of higher education institutions that offer programs in ABA, at an undergraduate or graduate level, as well as limited regulatory authorities that certify professional to practice ABA, and no national certification bodies. To our knowledge, there is only one postgraduate program in the emirate of Abu Dhabi, that offers a diploma in ABA. There are also currently two government authorities (Dubai Health Authority, and the Community Development Authority) both of which are based in the emirate of Dubai, who regulate ABA licensure. Therefore, adopting a parent-mediated approach to intervention may offer an immediate, cost-effective, solution to the limited access to trained professionals. It may also ensure greater impact whereby the parent is the direct interventionist and the main provider of effective practices across all daily contexts. Regarding providers of parent-mediated intervention, one approach could be to utilise a ‘pyramid’ or ‘task-sharing’ model, whereby non-specialists offer the first line of general intervention for children ‘at risk’ of ASD, cascading to more focused interventions implemented by specialists for children with more complex needs (Schlebusch et al., 2020). Utilising these approaches may offer a more scalable and sustainable solution to implementing parent mediated NDBI across a wider community within the context of limited human resources.

Socio-cultural Service Environment. An important contextual factor that may impact implementation of early intervention within the UAE is the social and cultural environment in which services are delivered. Al Abbady et al. (2017) reported that in Dubai, some parents may delay seeking ASD diagnostic evaluations, which was suggested to be due to cultural reasons. Social stigma associated with autism may be caused by cultural factors (Al-Kandari, 2006), and was described by Sopaul (2019) as a recurring theme in a qualitative study of families affected with Autism in Dubai. Further, feelings of stigma and denial experienced by parents of children with disabilities in the UAE may lead to a delay in access to intervention (Khamis, 2007). Sensitivity to a diagnosis of ASD was conveyed by some of the parents' who participated in our study, as discussed in chapter five. For some, the lack of a confirmed diagnosis of ASD was the reported reason for finding certain elements of the intervention irrelevant. This is important to consider, especially when providing intervention services for parents of children that have not yet received a confirmed diagnosis. This issue may stand in contrast to other countries whereby a neurodiversity movement has emerged emphasising and celebrating the advantages of autistic traits (Dawson, Franz & Brandsen, 2022).

Another factor to consider is the social norms of primary caregiving duties. In the UAE, parents often rely on nannies to perform many of the caregiving duties for their child (Sopaul, 2019). In some cases, these hired caregivers may be inexperienced and uneducated, lacking the skills to engage in positive social emotional interactions with the child (Roumani, 2005). In our study, parents acknowledged that they received caregiver support whether from a nanny or extended family member and attributed this to positive outcomes in generalisation of skills learnt. Consideration of who interacts most with the child on a daily basis, and who the primary caregiver is, is an important step in deciding who may benefit most from a ‘parent’ or caregiver mediated intervention.

Public knowledge and understanding of ASD may also impact implementation of intervention. Sopaul (2019) reported that parents of children diagnosed with ASD in the UAE expressed their difficulty in finding accurate information to support their understanding of ASD, and a confusion around how to support their child with evidence-based interventions. While outcomes from our study show improvement in parent knowledge, and a better understanding of their child post-intervention, parents may initially not choose to participate in an intervention program due to a lack of knowledge and understanding of Autism and its presenting symptoms – dismissing the need to intervene. In a study by Barbera (2007), a training program for parents of newly diagnosed children with ASD, facilitated by ‘expert’ parents of children with ASD who received previous training, showed that the transfer of knowledge on ASD was accurate and well received.

Inner Contexts

Organisational Characteristics. A critical factor in the implementation of innovative interventions into the community is the internal organisational support for evidence-based practice (Stahmer et al., 2019). Leadership ‘buy in’ in and support, whether in training or access to resources, can facilitate sustainable implementation of intervention. Further, ‘buy in’ from other members within the organisation who may play an integral role in the pathway of care may facilitate successful implementation through broader community reach. For example, a general paediatrician in a primary healthcare facility who identifies a child ‘at risk’ of ASD may be more likely to make a referral to a parent-mediated intervention program if they are informed about its structure and potential positive outcomes. Therefore, considering the internal organisation's characteristics is important when planning implementation.

Caregiver Characteristics. Considering caregivers needs and personal preferences is crucial in planning implementation of parent-mediated interventions. This may be in relation to the delivery of intervention (e.g., preference to keep video camera switched on during tele-coaching sessions, or language of instruction, or timings of sessions), or the content of intervention (e.g., need for supplementary material, personalised material to child behaviour difficulties, additional sessions, specific feedback). It is also important to consider where parents are on their journey of therapeutic change. For example, a parent who is experiencing doubts about whether they can help their child, may be less motivated to engage in the intervention. Therefore, starting with pre-intervention psychoeducation on the role of parents in teaching developmental milestones to their children, may improve their self-efficacy and motivate them to implement the learnt strategies.

Child Characteristics. Due to the heterogenous nature of autism, it is important to account for the wide variation in needs, skills, and circumstances of each child. Mediators of intervention, including a child's cognitive level; language skills; autism severity; or adaptive functioning, may potentially predict positive outcomes (Lord et al., 2021). Therefore, personalising a 'stepped care' model through flexibly adding and combining different modules based on childs' needs, mediators of intervention, and barriers to progress, may optimise treatment and improve outcomes (Kasari et al., 2018).

Innovation Factors

Considering the outer and inner contextual factors discussed, it is important to have flexibility and adaptability when implementing an innovative intervention in community settings within the cultural context of the UAE. To ensure a good contextual ‘fit’ between an intervention and the community, it first needs to be accessible to the target population. The availability of the material and instruction in both Arabic and English languages, which are the two most predominantly spoken languages in the UAE (Siemund et al., 2020), increases accessibility. In addition, addressing parents’ preferences by providing ‘add-on’ supplementary modules based on self-identified areas of need for their own child. Finally, offering intervention through telehealth addresses barriers, such as lack of time and geographical location, therefore, improving accessibility, affordability, and quality of services (Headquarters, 2018).

Another element that may increase the contextual ‘fit’ of the intervention is through adopting an adaptive stepped-care approach which takes into consideration the out and inner contextual factors discussed. This can be done through identifying the most appropriate caregiver to receive the intervention within each family/household, identifying preferences (e.g., language, privacy etc.), and understanding where the parent is on their journey of therapeutic change, and personalising and adapting elements of the intervention to enhance engagement.

Finally, consider workforce availability, and the socio-cultural service environment, adopting a ‘task sharing’ approach is an important factor to consider. This can be through cascading from non-specialist delivery of intervention (e.g., trained junior clinicians or parent ‘experts’) to specialist delivery for more focused or complex interventions.

Bridging Factors

To address the outer and inner contextual challenges of implementing early intervention in the UAE, it is important to involve stakeholders. This can be done through a research-community partnership which aims to address these challengers and improve communication between researchers and community partners to narrow down the research to practice gap. A successful example of how a research-community partnership can results in successful implementation of evidence-based intervention, is the Bond, Regulate, Interact, Develop, Guide, Engage (BRIDGE) collaborative (Rieth et al., 2018). This collaborative, which was developed in 2007, and consisted of clinicians, funding agencies, parents, and researchers with expertise in ASD, collectively addressed barriers in each phase of implementation, resulting in a publicly funded adapted intervention for toddlers with social communication concerns who were 'at risk' of ASD (Rieth et al., 2018; Stahmer et al., 2019). Outcomes from the BRIDGE collaborative demonstrate the achievement partnership synergy, high productivity, and meeting of their initial goals which included conducting a pilot study of a parent-mediated NDBI for toddlers 'at risk' of ASD, training of providers in the intervention, and children receiving the intervention (Brookman-Frazee et al., 2012).

Developing and Tailoring Implementation Strategies

In considering the contextual factors discussed, it is possible to identify the main barriers and facilitators to implementing a parent-mediated NDBI via telehealth and develop implementation strategies that are tailored to the local context of the UAE. Identified implementation strategies relevant to our intervention program, which include: a) engaging stakeholders through research-community partnerships; b) training and supervising non-experts to implement general intervention; and c) adapting and tailoring intervention to individual needs and preferences, will be discussed considering the Lancet recommendations for a stepped-care model for interventions in Autism (Lord et al., 2021).

Engaging Stakeholders Through Research-Community Partnerships

To successfully implement effective evidence-based intervention services in the community, it is important to develop plans to action policies, and mobilise funding for community-based intervention programs. This can be achieved through the involvement of stakeholders including autistic individuals, researchers, policy makers, funding agencies, expert professionals, parent advocates, and Autism societies. Stakeholder involvement through establishing a research-community partnership can facilitate the actioning of existing policies. Parents led organisations, especially, can be powerful advocates of service provision for children with ASD through their demands on individual providers, funding agencies, and legislators (Stahmer et al., 2019). Over many decades, parent advocacy groups have played a critical role in policy, practice, and research across the globe, leading to more evidence-based treatment options and earlier diagnoses for children with ASD (Lord et al., 2021). In developing strategies to facilitate successfully adopting a novel intervention, the Lancet commission reporting on the future of care and clinical research in autism argue the importance of starting with "Engaging stakeholders in the development and adaptation of intervention" (Lord et al., 2021, p. 50).

Training and Supervising Non-Experts to Implement General Intervention

To address the scarcity of trained professionals with expertise in evidence-based interventions for ASD in the UAE, and the high cost of providing therapist led evidence-based interventions, adopting a cascade model for coaching parent-mediated interventions may offer a feasible solution. Trained non-experts can be supervised to provide the 'first line' of general intervention, and data-based decisions can be made to 'step up' the care for more complex cases to receive intervention from more specialised professionals. The Lancet commission describe 'task sharing' as a key principle in stepped care, whereby, "services are provided whenever possible by the least expensive and most accessible provider, with supervision and training provided by more highly trained professionals" (Lord et al., 2021, p. 22).

Trained parent experts may also play a role in providing accurate, evidence-based, information about the characteristics of Autism, reasonable expectations from intervention, and the importance of their role in supporting their child's development, to parents with newly diagnosed children with ASD, or importantly awaiting diagnosis. A pre-intervention programme that aims to educate parents of children 'at risk' of Autism on child developmental milestones and challenges in social communication and interaction may improve their likelihood of participating in interventions aimed to target these developmental milestones and specific behavioural targets. The Lancet commission highlights the importance of psychoeducation as an essential step in implementation of intervention for children with ASD and argues that parents "need opportunities to learn about autism in general, the characteristics of the 'identified patient' specifically, and the potential benefits and limitations of what professionals and systems can offer within locally available care systems." (Lord et al., 2021, p 23-24).

Adapting and Tailoring Intervention to Individual Needs and Preferences

Given the heterogeneity of Autism, perhaps the most important aspect in implementing an adaptive intervention within a stepped-care model, is the personalisation of the intervention, considering parent and child individual preferences and needs, within the cultural context of the UAE. This can be done through pre-intervention interviews that can elicit information about the family context and natural environment, such as: who is the most 'suited' caregiver to receive the intervention may be; what behavioural targets should be prioritised at specific timepoints; preferences in mode of delivery of intervention; personal costs and risks; and perceptions of their child's abilities and their role in intervention. This information may facilitate a truly adaptive approach whereby modules can be combined and delivered based on needs and preferences of caregivers. The Lancet commission stresses the importance of taking into account the family's' "needs, abilities and 'personal costs' (not just financial)" (Lord et al., 2021, p.23), when implementing a stepped-care model of intervention, and propose incorporating "participatory decision making in clinical practice" (Lord et al., 2021, p.23).

There is also an emphasis on addressing multiple components when delivering intervention and includes approaches for skill building, and minimising challenging behaviours that are a barrier to progress (Lord et al., 2021). Therefore, in line with outcomes of our study discussed in chapters 4 and 5, regarding the need for more modules on managing difficult behaviours and promoting language and communication, it is important to incorporate components and additional supplementary modules that target these needs. This is especially relevant in the context of the current research whereby the content emphasised developmental cusps to acquire skills rather than reduce difficulties. This can be achieved through the introduction of evidence-based behavioural interventions for example Functional Communication Training (FCT) plus Differential Reinforcement modules and coaching, which have been demonstrated to result in a decrease in challenging behaviours and an increase in more effective alternative responses e.g., manding (vocal or non-vocal requesting). In a study by Rispoli et al. (2023) investigating a telehealth coaching in FCT for caregivers of young children with neurodevelopmental disabilities demonstrated, outcomes show an increase in caregiver FCT implementation fidelity, as well as a decrease in challenging behaviours and increase in functionally equivalent responses, presenting further evidence supporting the use of telehealth as a modality for caregiver training.

For some children who may not achieve their targeted developmental milestones, and are identified as 'non-responders' to educational interventions, adding intensity through utilising specific ABA evidence-based practices may offer a more focused approach to skill acquisition. These focused evidence-based practices identified by Hume et al. (2021), may be used as components of an intervention programme, that are matched based on the specific needs and learning goals of children with autism. This can be facilitated by existing resources, such as the Autism Focused Intervention Resources and Modules (AFIRM), which are accessible online modules, based on the identified evidence-based practices, that were made available through a freely accessible website (Sam et al., 2019). Another factor to consider for 'non responders' to intervention, is the difference in neurobiological aetiologies and possible co-morbid conditions, which may indicate the need for further psychopharmacological interventions, for example, for severe challenging behaviours or co-morbid Attention Deficit Hyperactivity Disorder |(ADHD) (Bitsika & Sharpley, 2023).

Finally, in making data-based decisions to personalise a stepped-care model of intervention, it is important to consider other mediators of intervention and factors that may predict positive outcomes, including the child's cognitive level, language, skills, autism severity, and level of adaptive functioning (Lord et al., 2021). It is important to consider that for some children with Autism that present with severe intellectual disability or very limited language, what is referred to as 'profound autism', there may be different educational and functional needs that need to be identified and planned for (Lord et al., 2021). Although the Lancet Commission (Lord et al., 2021) deems the term 'profound autism' as not appropriate for children younger than 8 years, since these factors may change, it is important to understand that language and intellectual abilities may be a significant mediator of intervention, which can indicate a more rapid stepped care approach to support an improved quality of life for the child and their family. There is limited information on how child characteristics and mediators of intervention impact intervention outcomes within the context of the UAE. This is an area to be targeted in future research, to inform decision making when implementing adaptive stepped-care interventions in this geographical location.

A summary of the proposed implementation strategies discussed is presented in relation to targeted barriers and facilitators, and corresponding Lancet Commission recommendations for a stepped-care model, in Table 6.1 below.

Table 6.1

A Summary of the proposed implementation strategies in relation to targeted barriers and facilitators and Lancet Commission recommendations for a stepped-care model.

Implementation Strategy	**Targeted Barrier/Facilitator**	**Corresponding Lancet Commission Recommendation (Lord et al., 2021)**
Engaging stakeholders through research-community partnerships	Gap between policy and practice	Stakeholder involvement
	Lack of public funding for early intervention in Autism	
	Unclear referral pathways for children 'at risk' of Autism	
Training and supervising non-experts to implement general interventions.	Scarcity of trained professionals	Task-sharing
	High cost of therapist led evidence-based interventions	Psychoeducation
	Limited understanding of Autism and parents' role in their child's development	
Adapting and tailoring intervention to individual needs and preferences	Heterogeneity of Autism	Considering heterogeneity of Autism, and diversity of family and cultures
	Socio-cultural differences	Considering 'personal cost' to families
	Context of natural environment and caregiving duties	Addressing multiple components of needs
	Journey of therapeutic change and parent perception of their role in intervention	Considering caregiver preferences and needs
	Data-based decision making	Data-based decision making
	Flexibility	Addressing barriers to progress by supporting in behaviour reduction
	Bilingual Intervention	Considering mediators of intervention that predict positive outcomes

The implementation strategies proposed aim to address the identified barriers and facilitators of delivering a parent-mediated intervention delivered via telehealth within the context of the UAE to improve outcomes of young children, diagnosed or ‘at risk’ of ASD, and their families. The contextual factors identified using the EPIS framework, and the implementation strategies proposed, may contribute to future research aiming to successfully adopt evidence-based interventions into community settings in other low- or middle-income countries in the region.

Chapter 7

General Discussion

The National Research Council (2001) recommend that intervention for children diagnosed with Autism should begin as early as possible, at a minimum of 25 hours per week of active engagement in developmentally appropriate, and purposeful, instructional activity, and include the active participation of parents in the intervention process. It has been established that best practice in early intervention for autistic children involves strategies based on the principles of Applied Behaviour Analysis (ABA), in particular, Early Intensive Behaviour Intervention (EIBI), which is a comprehensive approach that focuses on skill acquisition (e.g., language, play, social interaction, imitation, motor skills etc.), and reduction of challenging behaviours that may present a barrier to learning. Delivery of EIBI in combination with parent training and supporting transitions into naturalistic environments (i.e., everyday life), can promote generalisation and a positive spill over into everyday life and living (Healy & Lydon, 2013).

Young children who are identified before the age of three years and begin very early intervention show more positive outcomes compared to children diagnosed later (Pierce et al., 2016), with sustained improvements in social communication domains and in adaptive behaviour and cognition (Estes, Munson, Rogers, Greenson, Winter & Dawson, 2015; Green et al., 2017). Best practice in interventions for children below the age of three years with suspected or confirmed autism is to include behavioural and developmental approaches as early as possible, and ensure active involvement of parents (e.g., Zwaigenbaum et al., 2015). Naturalistic Developmental Behaviour Interventions (NDBIs) is an evidence-based approach that integrates the principles of both ABA and developmental science, particularly well suited to the toddler autism population, as it has shown to result in accelerated child learning and behaviour change (Schreibman et al., 2015). NDBIs are implemented in natural everyday settings where learning opportunities can be embedded, utilising natural contingencies to teach developmentally appropriate skills, specifically during play and daily life activities (Schreibman et al., 2015). A growing body of research in NDBIs has demonstrated positive effects including improvements in cognitive, linguistic, and adaptive behaviours, as well as reduced severity of core symptoms of ASD in toddlers (Dawson et al., 2010; Estes et al., 2015)

A crucial element in the success of early intervention, especially for toddlers, is parental involvement. Parent-mediated intervention is an approach whereby professionals support parents in fostering their child's learning and development, across natural everyday activities (e.g., mealtimes, bath time, play etc.), by embedding intervention strategies (Wetherby et al., 2018). This modality of intervention has gained increased attention in the past decade, with a growing body of research examining its effectiveness for young children with early indications of autism (Tomeny et al., 2019). More specifically, in a recent systematic review by Pacia et al. (2021), it was reported that parent-mediated intervention models that are based on NDBIs, including the Early Start Denver Model (ESDM), were established as evidence-based practice for young children with autism. Successful parent-mediated intervention models involve professionals *coaching* parents to facilitate their child's learning by building on the parent's own ideas, experience, and knowledge through collaboration and reflective practices (Tomeny et al., 2019; Vismara & Rogers, 2018).

Despite strong evidence supporting the importance of early intervention in increasing positive outcomes, as well as reducing the lifetime associated societal costs, there are major barriers that prevent young children from accessing evidence based early intervention (Wetherby et al., 2018). The scarcity of resources and increased demand for services has contributed to a surge in waitlists for ASD diagnostic evaluations, and a delay (up to 3 years) in receiving early intensive behaviour intervention in the community (Wainer et al., 2021). For families living in less urbanised areas, these delays are further magnified due to the lack of local service providers, and financial and time burdens of travelling long distances to avail of these services if available (Ferguson et al., 2019).

Utilising telehealth, which is a model of delivering therapeutic services at a distance, can potentially narrow the service-need gap and increase the availability of empirically supported interventions for young children with autism. Providing early intervention services, and parent training, via telehealth can enable families to receive services in a timely and cost-effective manner in the child's natural setting and may thus enhance the quality of services available to families living in remote areas (Boisvert & Hall, 2014), harnessing precious time during the crucial early years of neurodevelopment (Ozonoff et al. 2010). Ferguson and colleagues (2018) reported that telehealth was shown to be an effective and feasible platform in increasing both parent's knowledge and implementation of skills based on behaviour analytic interventions. Further, utilising a hybrid telehealth approach, integrating both self-directed (asynchronous) and parent coaching (synchronous) formats, can be more effective in parent-mediated interventions, compared to self-directed learning alone (Ingersoll & Berger, 2015; Wainer et al., 2014;).

The Lancet Commission on the future of care and clinical research in autism published a set of newly established recommendations that include the utilisation of a novel 'stepped care' or personalised health model for intervention in Autism (Lord et al., 2021). Wainer and colleagues (2021) studied an adaptive intervention, whereby a stepped-care approach was followed through offering less intensive intervention as a first-line treatment and intensifying the intervention when clinically indicated. This approach showed strong acceptability, improved parent fidelity of intervention, and improved self-efficacy. Telehealth interventions that are scalable, open-access, caregiver-mediated and delivered as part of a stepped care approach have the potential to begin to address the global treatment gap for families of children with autism (Pacione 2022).

Interventions for children younger than three years with either early indications of, or established diagnosis of ASD, are recommended to consider sociocultural beliefs of the family, and further research is needed to include culturally diverse populations to evaluate factors that may affect participation, acceptability, and outcomes (Zwaigenbaum et al., 2015). The heterogeneity of Autism is not only reflected in the variation in clinical presentation, but also in the diversity within families, cultures, and countries given the global scale of prevalence (Lord et al., 2021). Early intervention research and programmes have been predominantly developed in non-representative populations in high-income countries, and typically designed to fit their context (Nielsen et al., 2017). Research that facilities immediate impact on the improvement of individuals with Autism and their families' lives across diverse communities and cultures must be prioritised if improvements are to be realised globally.

A literature review by Alkhateeb et al. (2022) of the impact of ASD on parents in Arab countries reported a social, psychological, and financial burden, associated with different factors including severity of ASD, social support, maternal education, parental age, gender of child, and economic status. In the UAE, ASD is considered as one of the major challenges in the healthcare, educational and social services sectors, and policies and legislations specific to Autism are still in their infancy. Recently, in April 2021, the UAE cabinet approved 'The National Policy for Autism' (UAE Ministry of Community Development, 2023). However, there remains a gap between policy and practice, as there are currently no formal pathways or national guidelines for autism diagnosis and interventions. Further, there is a lack of service provisions in less urbanised cities, or remote areas, of the UAE.

To the best of our knowledge, there are no published studies to date investigating the impact of early interventions for young children diagnosed with, or at risk of autism, in the UAE. The current research programme aimed to explore the introduction of a parent-mediated NDBI delivered via telehealth to parents of toddlers ‘at risk’ of autism in the UAE, with a view to developing a contextually fit intervention programme that can be adopted and implemented within the community setting. The aims of the research programme were: 1) to develop a bilingual parent-mediated NDBI programme and outcome measures; 2) to investigate the feasibility and acceptability of an adaptive parent-mediate NDBI delivered via telehealth; 3) to investigate the impact of an adaptive parent-mediated NDBI delivered via telehealth on parent knowledge, family experience, and parent reported child outcomes; 4) to explore parents attitudes toward and engagement in an adaptive parent-mediated NDBI delivered via telehealth; and 5) to explore the barriers and facilitators of implementing a parent-mediated NDBI via telehealth within the context of the UAE.

Contributions of the Current Research Programme and Overview of Findings

Overview of Study 1 (Chapter 2)

The first aim of the research programme was to adapt and develop a contextually fit, bilingual (Arabic and English), parent-mediated NDBI programme, based on the ESDM, as well as to develop and/or translate outcome measures into Arabic. This process was informed by experiences from a small-scale pilot trial conducted during the COVID-19 pandemic at Al Jalila Children’s Specialty Hospital (AJCH) in Dubai, UAE. While parents reported the intervention to be acceptable and described it to be helpful in facilitating improved parent-child interactions, the experience highlighted the importance of adapting a culturally and contextually fit intervention that takes into account some of the initial barriers and facilitators identified. As a result of this, pre-recorded video modules were created, based on topics and strategies from the ESDM parent manual (Rogers & Dawson, 2012), in both Arabic and English instruction, in addition to supplementary material to solidify learning. In considering the cultural and contextual validity of the outcome measures, a multi-step process of back translating three outcome measures, including the Autism Family Experience Questionnaire (AFEQ) (Leadbitter et al., 2018) and the Social Communication Checklist – Revised (SCC-R) (Weiner et al., 2017), was undertaken. In addition, two measures, the Attitude and Engagement in Intervention Questionnaire (AEIQ) and a Behaviour Vignette, were exclusively developed for the research programme.

Overview of Study 2 (Chapter 3)

The aim of the second study of the research programme was to examine the initial feasibility and acceptability of individual and group-based coaching of parent mediated NDBI delivered via telehealth to parents of toddlers 'at risk' of Autism in the UAE, as well as develop an understanding of the impact of such an intervention on parent knowledge and parent reported child outcomes. A randomised three group experimental design with pre/post-test was conducted. A total of 19 parent participants were recruited from the AJCH autism diagnostic evaluation 'waitlist' to participate in the 10-week intervention cycle via telehealth. Participants were randomly allocated to either Psychoeducation only (PE) group, who received online modules only and served as a control group; an Individual-Coaching Parent Mediated Intervention (I-CPMI) group, who received online modules in addition to individual tele-coaching sessions; or, a

Group-Coaching Parent Mediated Intervention (G-CPMI) group, who received online modules in addition to group tele-coaching sessions. Following attrition, a total of 14 participants completed the study. Outcomes from the study supports the initial feasibility and acceptability of a parent-mediated NDBI delivered via telehealth in the UAE, as well as reported improvement in parent knowledge and parent reported child outcomes, for participants who received parent coaching. However, limitations and challenges from the study, including high attrition, highlight the importance of adopting an adaptive, stepped-care, approach to delivering an intervention that is personalised to parent needs and preferences, as well as account for the diversity within the context of the UAE.

Overview of Study 3 (Chapters 4 and 5)

The focus of the third study was to investigate an adaptive parent mediated NDBI delivered via telehealth to parents of toddlers diagnosed with, or at risk of, ASD in the UAE by adopting a hybrid, mixed methods, research design incorporating both quantitative and qualitative data. The aim was to understand the feasibility and acceptability of the adaptive intervention; the optimal sequence and intensity of the adaptive intervention; and the impact on parent knowledge and engagement as well as parent reported child outcomes.

A Sequential Multiple Assignment Randomised Trial (SMART) design, which involves assigning participants to different sequences of interventions at specific time points based on the status of their response, was chosen to conduct our investigation, as it is a useful tool when building and evaluating an adaptive intervention (Buchholz et al., 2020), and facilitates the rapid evaluation and delivery of optimal interventions (Lauffenburger et al., 2022). A total of 20 participants completed a six-week intervention cycle, receiving different sequences of intervention. Participants were initially randomly allocated into one of two groups, Modules only (M) or Modules in addition to

Asynchronous Parent Coaching (M+APC). Based on their response to intervention at week three, parents were either randomly re-allocated to sub-groups who received different form of augmented intervention (slow responders), including weekly or single coaching sessions, or continued to receive the same intervention (responders). This resulted in a total of six adapted sequences of interventions that were analysed. Results from the study support the feasibility of a brief adaptive intervention of coaching parent mediated NDBI delivered via telehealth. Preliminary findings suggest that utilising a rapid measure of response to intervention is a useful tool to identify slow responders, and that augmenting intervention with parent-coaching leads to more positive outcome, including improved parent knowledge of environmental modifications and alternative behaviours; decreased burden of autism on family experience; parent reported improvement in social engagement, communication, and play; and improved parent response to intervention. Although most parents reported the intervention to be feasible, acceptable, and appropriate, there were some limitations that need to be considered when interpreting the outcomes, including small sample size, lack of observation-based measures of fidelity of implementation and child outcomes.

The focus of Chapter 5 was to gain an in-depth understanding of parents' attitudes, perceptions, and experiences from engaging in the intervention programme. To achieve this, qualitative data from semi-structured interviews conducted post-intervention were analysed in an aim to investigate the social validity of the intervention within the context of the UAE, as well as identify potential barriers and facilitators of implementing the intervention. A total of seven themes emerged from the data, relating to either parents' opinions on characteristics of the intervention programme, or perceptions and attitudes towards intervention. While parents perceived the flexibility, accessibility, and general structure to be strengths of the intervention programme, they identified some gaps, including the need for supplementary material covering challenging behaviours and communication, as well more practical demonstrations. Identified facilitators include parents' feelings of empowerment, the willingness to invest time, the therapeutic relationship between parent and clinician, acceptance and understanding of the child's needs, and applicability in daily life. Regarding barriers, parents' acceptance of their child's challenges, and their understanding of the importance of their role as their child's primary interventionist were major factors that impacted parent engagement in the intervention, in addition to parental demands of daily life. These facilitators and barriers are important to consider when planning implementation of the intervention within the local context.

Overview of Study 4 (Chapter 6)

The final aim was to explore the identified barriers and facilitators in implementation of an adaptive parent mediated NDBI delivered via telehealth and develop and tailor implementation strategies that are contextually fit. In line with implementation science, the Exploration, Planning, Implementation, Sustainment (EPIS) framework was utilised to methodically tailor implementation strategies based on identified barriers and facilitators within the context of the UAE. Identified outer contextual factors (funding, human resources, socio-cultural service environment), and inner contextual factors (organisational characteristics, caregiver characteristics, and child characteristics), informed the development of three implementation strategies that aim to target barriers and facilitators described. The implementation strategies, including: a) engaging stakeholders through research-community partnerships; b) training and supervising non-experts to implement general intervention; and c) adapting and tailoring intervention to individual needs and preferences, were discussed in the context of the recent Lancet recommendations for a stepped-care model for interventions in Autism (Lord et al., 2021).

Challenges and Limitations of the Current Research Programme

The challenges and limitations from each study have been extensively discussed throughout the chapters and include small sample size, attrition rates, and use of parent-reported measures for primary outcomes. However, there were broader challenger and limitations faced across all phases of the current research programme and will be discussed below.

Participation in Research

A significant challenge faced throughout this research programme was the recruitment of parent participants. Despite there being a large number of parents that met criteria to be included in the study, and expressed interest in the intervention, only a few confirmed their participation and completed the process of consent. Further investigation needs to be conducted to understand whether there is a social stigma associated with involvement in Autism research in the UAE, or whether there are other variables that contribute to the lack of motivation to participate in research, such as the demand on time or burden and disruption of daily life (Tromp et al., 2016). Another challenge was maintaining parent participants' motivation and engagement in the operational aspects of the study, including completing outcome measures, despite making considerable efforts in selecting valid and brief outcome measures that did not require a substantial amount of time to complete.

Resources to Engage in Large-Scale Research

A limitation of the current research programme, which presented considerable challenges throughout conducting the studies, was the lack of resources available. First, the primary investigator was the same person who recruited participants, delivered the interventions, conducted data collection, and analysed the results. This presented a challenge and posed restrictions on our ability to blind the study to increase the validity, conduct observations of parent fidelity in implementation and child observations to validate parent reported outcomes. Future research should consider the use of validated observation tools that can be utilised through video-conferencing platforms or by viewing pre-recorded videos. One useful observation-based measure to evaluate implementation of NDBI strategies during early intervention is the Measure of NDBI Strategy Implementation – Caregiver Change (MONSI-CC) (Vibert et al., 2020). Another observation-based measure of treatment response in ASD intervention, that captures changes in ASD symptoms, is the Brief Observation of Social Communication Change (BOSCC) (Grzadzinski, 2021). Finally, due to the lack of resources to undertake the current research programme, there was no follow-up conducted to understand the maintenance of knowledge and skills learned and the long-term impact of the intervention on child behaviours as well as generalisation of skills developed to other caregivers and within different settings.

In the development of the parent training program within the context of the EPIS implementation framework, a notable limitation arises from the absence of a systematically applied theory of change during the exploration and preparation phases. The utilization of a theory of change, which is a method that explains how an intervention is expected to lead to development change, is imperative for elucidating the underlying assumptions, causal pathways, and mechanisms through which interventions are expected to bring about desired outcomes (Douglass, Halle, & Tout, 2019). Although moderator and mediators of intervention were described in chapter 6, in the absence of a robust theoretical foundation during the exploration and preparation phases, there is a risk of overlooking essential components of the complex socio-ecological context in which the parent training program is to be implemented. This may hinder the establishment of clear and measurable objectives, impeding the alignment of intervention strategies with intended outcomes. Addressing this limitation is crucial for enhancing the theoretical underpinnings of the parent training program and ensuring its relevance and efficacy within the broader EPIS implementation framework.

Future Implications

Research

There is a significant gap in research on evidence-based interventions for Autism in Arab cultures or countries, and there is an emphasis on the importance of prioritising this in order to inform services with culturally relevant evidence (Alallawi et al., 2020). The current research programme is the first to investigate an adaptive parent-mediated NDBI delivered via telehealth in the UAE and propose a contextually fit implementation plan based on barriers and facilitators relevant to the local context. Given the scarcity of ASD intervention studies conducted in low to middle income countries, the current research programme can inform future research in neighbouring countries within the region, and potentially other low to middle income countries.

An area to explore in future research within the region, is the fathers' role in the identification and intervention of toddlers 'at risk' of Autism in the UAE. Fathers of children identified 'at risk' of, or diagnosed with Autism, are under represented in both research and practice, despite having unique interaction styles that may contribute to positive outcomes for their child and their family (Flippin & Crais, 2011). Despite having two fathers participating in our pilot trial conducted during the COVID-19 pandemic, there were no fathers that opted to participate in our pilot study, or adaptive intervention study. One explanation might be the availability of time for fathers participating during the COVID-19 trial, since restrictions were in place at the time and work was being conducted ‘at home’, allowing for more time to engage in parent-mediated intervention. In addition, during recruitment for both the pilot and adaptive intervention studies, fathers that were contacted by the primary investigator opted to delegate the matter of participation in the described intervention to the mother, with some being unaware that their child was identified as ‘at risk’ and referred for intervention. It is important to explore the impact of cultural factors and societal expectations on the roles fathers undertake in autism intervention within the UAE. Future research should explore fathers’ perceptions of having a child identified as ‘at risk of Autism, and their perceived role in intervention. Another consideration is to understand what factors may have a positive impact on improving fathers’ participation in intervention, such as, having father ‘champions’ or advocates speaking publicly to raise awareness and influence paternal engagement, or government policies that allow for fathers who are engaged in full-time employment to have allocated, paid, time off work to facilitate involvement in their child’s intervention.

Practice

Parent-mediated NDBIs remain severely underutilised in both high-income countries and low to middle-income countries, despite it being considered an evidence-based practice (Rieth, 2022). This may be partly due to the unsuccessful integration of parents in the intervention process, which are exacerbated by inadequate provider training; and challenges in parent engagement, which may be a result of differences amongst parents in their motivation, skills, stress levels, perceived efficacy of intervention, self-efficacy, and perceived burden of the intervention on family life, amongst parents (Reith, 2022). Therefore, future implementation efforts should focus on the dynamic training of intervention providers in parent engagement techniques that are culturally and contextually fit, as an essential component prior to the delivery of an adaptive stepped care model of parent mediated NDBI.

It is also important to consider the treatment or process integrity of the intervention provided when implementing research or in clinical practice. The strength of the parent-coaching sessions lays in its individualised nature, with personalised approaches adapted to each parents' needs, guided by motivational interviewing. Monitoring of treatment or process integrity may pose a challenge due to its adaptive nature. However, creating a 'checklist' that describes the general structure of the sessions may offer a practical solution to monitoring treatment or process integrity.

Regarding coaching parents, it is important to take an expansive view when considering primary caregiving roles, and who might be best suited to provide parent/caregiver-mediated interventions. Traditional models of parenthood, whereby the biological mother and/or father are the primary caregivers, may not be the norm within certain cultures and contexts (Schlebusch et al., 2020). In the UAE, children under the age of 10 years are often cared for by a nanny or housemaid, which is considered the social norm in the region (Roumani, 2005). These caregivers are mostly un-credentialed or un-trained to provide early childhood care (Taha-Thomure, 2022). To ensure more positive outcomes on a child's social emotional development from a caregiver-mediated intervention, it is important to consider providing pre-intervention training in caregiving skills, as a pre-requisite prior to receiving coaching of caregiver-mediated NDBI.

Pre-requisite training, or intervention 'readiness' training programs, that are offered prior to initiating coaching of parent-mediated NDBI, may also be a useful solution that can target new parents who may have a limited understanding of general parenting skills. This can be offered to parents who are identified through a pre-intervention interview. One promising program being piloted in the emirate of Abu

Dhabi, in the UAE, is a culturally fit parenting program, launched by the Abu Dhabi Early Childhood Authority, that aims to augment parent knowledge and skills in the developmental domains of health, nutrition and early learning, targeting parents with children under the age of 8 years (The Abu Dhabi Early Childhood Authority, February 3rd, 2024). Offering such a program may place parents at a better position to benefit from parent-coaching of NDBI for toddlers ‘at risk’ of ASD.

Finally, one consideration is the cultural implications of providing tele coaching of parent-mediated NDBI in the UAE. Telehealth has transformed the landscape of healthcare delivery, particularly in the realm of interventions aimed at fostering child development and parental/caregiver training. In the context of the UAE, where telehealth interventions have gained prominence, the use of video cameras plays a crucial role in shaping the therapeutic relational connection between the interventionist and the training recipient. The therapeutic alliance, an essential component of effective interventions, relies heavily on non-verbal cues, visual engagement, and the establishment of a meaningful connection. Understanding the intricacies of camera usage in the UAE's cultural and socio-technical context is paramount, as it not only influences the efficacy of interventions but also informs best practices for optimizing the therapeutic relational connection in the burgeoning field of telehealth. Future research should examine the impact of maintaining cameras off, to unravel the potential impediments to the development and maintenance of a robust therapeutic relationship.

Final Conclusions

Despite the challenges and limitations experienced, utilising telehealth in the delivery of a parent mediated NDBI is a promising solution that can improve outcomes for parents and young children diagnosed with, or at risk of, autism in the UAE, and enhance their quality of life. Given that the UAE is at its early stages of establishing pathways to action federal Autism policies for assessment and intervention, there is an opportunity to advocate for the use of innovative, culturally-fit, evidence-based approaches in how services are provided. The key contribution of this research programme is the creation of a bilingual (English and Arabic) adaptive parent-mediated NDBI program designed to be delivered via telehealth, the translation and development of bilingual content and outcome measures, and the development of an implementation roadmap for the context of the UAE. Further investigations are imperative to test these contributions to scale.

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