Designing a Parent-Driven Coaching System for Indirect Speech Therapy

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Abstract

Based on UK Department of Education annual report 2017, seven percent of preschool children experience speech and language developmental delays. The report goes on to argue that these delays negatively impact success at school. Such delays are more common amongst children with cerebral palsy or autism. Early intervention therapy is recognised as being vital in minimising the long-term impact of such delays and the responsibilities for delivering such therapies most often lies with parents or primary carers. Therapists typically support parents by providing speech and language therapy sessions. The primary goal of these sessions are; to teach the parents techniques to promote the children's communication skills, identify communication opportunities, and adopt and adapt learned communication strategies in their everyday interactions with the children in their natural environment. While parent-delivered therapies can alleviate the demand on therapists and healthcare services by reducing the amount of professional contact time, they can also create an overwhelming burden on parents.

This thesis is an in-depth exploration of early speech therapy programs and identifies the values and support needs that can used to understand the parents' and therapists' experiences as well as identify indictors to improve therapy adoption in this context. Additionally, this research investigates the role of coaching technology in improving communication and collaboration between parents. New parent-driven coaching technologies to support reflections on home practices and address the challenges of home therapy delivery is also presented. A case study approach is undertaken to explore this area with two different clinical partners and therapy protocols. Each study commences with a contextual investigation and moves toward co-design and evaluation of digital solutions with therapists and parents. The first case study, eSALT, presents the design of KeepCam, a parent-led selective data capture and sharing tool to support parents of children with cerebral palsy. The second case study presents the design of ePACT, a self-reflection tool to support parents of children with autism. This thesis reports on how mobile video coaching tools can be used as an external drive for continuous engagement with therapy programs and facilitate social support. It also identifies opportunities for technology to play important roles in supporting early therapy programs. The thesis draws upon these case studies to inform the design of a responsive model of support for indirect therapies, through which the role of design and power relations in healthcare are explored.

To the Memory of My Father,

I Really Miss You!

To My Everything,

My Mother & My Story

To My Dearly Beloved Sisters,

Nouf & Noura

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Chapter 1. Introduction

1.1 Overview

Early childhood plays a crucial role in children's development to the extent that a child's progress is noticed in terms of multiple physical, social, cognitive, language and communication skills. For instance, children get their first tooth at 6-9 months, start walking at 10-18 months, say their first words and develop understanding at 12-18 months (NHS 2019); in turn, failing to meet a development milestone might be an indicator of developmental delay. In early years, child development is monitored by primary-care providers who conduct the necessary clinical assessments when signs of developmental delays appear e.g. not being able to crawl by 12 months. This early assessment is then followed by referrals to the appropriate early intervention when delays are clinically identified (Simard et al. 2014).

Several developmental delays may occur during the early stages of childhood. Speech and language delay is one of the common developmental delays in young children (Shong & Cheng 2007), where 7% of preschool children experience speech and language developmental delays (Roulstone et al. 2011). Generally, when children do not meet the expected milestones for speech and language – for example, not being able to babble at 6 months old – this is considered a delay. In fact, several conditions are thought to cause the speech and language delays. As such, speech and language delay can be classified as a secondary characteristic associated with other developmental problems or disorders, such as cerebral palsy or autism spectrum disorder (McLaughlin 2011).

Speech and language delays in early childhood can lead to a child's exclusion from social and educational activities. Here Schmidt and Lee have demonstrated the importance of early therapy intervention for coping with any speech and language delay (Schmidt & Lee 2005). Early Speech and Language Therapy (SLT) is often provided as an early home-based intervention shown to improve preschool children's communication skills before they reach school age (Majnemer 1998; Diggle & McConachie 2009; Pennington et al. 2004). Early SLT aims to help children develop speech, language and communication skills in order for them to become independent communicators. However, owing to their disabilities, some children may

not use intentional speech or become independent communicators; in the latter case, Early SLT may facilitate the development of alternative communication patterns.

Home-based therapy involves coaching parents to identify and response to their children's communication signals, while adopting therapy techniques in their daily interaction to improve their children skills. The therapist demonstrates the communication protocol to the parents through the therapy sessions, allowing them to apply it at home without the therapist's presence. This form of early SLT is also known as *indirect therapy*, *home therapy programmes* or *parent-delivered therapy* - we will use these terms interchangeably throughout the thesis.

The rationale behind early therapy technique is to emphasise the role of parents in promoting their child's communication skills at this very young age. In turn, parents are seen as the ideal candidates for delivering speech therapy to preschool children in their natural environment because they are their primary communication partners (Majnemer 1998; Baxendale & Hesketh 2009). The parent's role is fundamental because the recognition of, correct modelling of and extension of speech need to be provided as soon as the child acts or vocalises. For example, when a child points to a cup, the parent usually says "cup" and repeats the action to develop the child's skills (Pepper & Weitzman 2004). Infrequent communication may have a significant impact on the development of speech; repeated practices on the part of parents are thus critical to promote the child's communication skills (Schmidt & Lee 2005).

Although the beneficial outcomes of early SLT have been recognised, indirect therapy for young children (i.e. preschool children below five years old) has so far been designed with a limited number of therapy coaching sessions for parents to access. These are often held as group sessions. Due to high demand and limited resources, the current organisation of the therapy services cannot accommodate frequent therapy sessions (Gascoigne 2012). The unfortunate consequence is that parents may lose technical, social and moral support from their therapist as a result of infrequent sessions (MacKintosh et al. 2012; Boyd 2002).

In addition, given the prevalence of parent-delivered therapy technique for preschool children, parents now face several challenges in adapting their communication behaviour to promote their children's speech and language development. Owing to long intervals between visits, parents may struggle to validate their practices and continue to pursue the behavioural

techniques that they have been advised to use (Kientz et al. 2009). In addition to the lack of support from the therapist, parents may be contending with busy daily lives, forgetfulness or other psychological factors that may prevent them from applying the communication practices in question (Kientz et al. 2009).

Furthermore, the limited contact by therapists may reduce the support that they can provide to promote parents' use of communication techniques and ensure that parents are practising these techniques correctly. The amount of time and resources given to SLT is a policy decision on the part of the health service provider (Gascoigne 2012). Hence, it is not principle that prevents families from having continuous support, but a resource issue. For example, the current policy admits limited contact with therapists, entailing that approaches to augment this support or optimise contact are highly desirable (e.g. through remote coaching).

Given the impact of parents' interaction patterns on children's communication development and alternative forms of services delivery (Tse et al. 2015; Aggarwal et al. 2015), we should consider the role that digital technology could play in helping parents to support their child's communication behaviour. By introducing mobile technology for video coaching, parents can access the required input of their therapists remotely, so giving feedback on their home practice with their children. In previous parent-child interaction research, video recording has been introduced in clinical settings and research environments for reflections and assessments (Leung & Kao 1999; Hwang et al. 2014; Pennington et al. 2003; Pennington et al. 2009; Fey et al. 2006; Green et al. 2010). Moreover, the power of video capture for behaviour assessment or remote session delivery has been demonstrated in different contexts with various special needs (Mamykina et al. 2008; Aggarwal et al. 2015; Cason 2011; Hayes et al. 2008).

However, early SLT programmes depend heavily on parents and, as we will demonstrate in Chapter 2, the support provided to their application of home therapy has received less attention compared to technologies designed for clinical assessment or remote therapy session delivery. In fact, until recently, video recording in daily life and at home has been difficult because video cameras were unwieldy and difficult to set up, which was likely to affect the communication environment. Nowadays, parents often use their smartphones to record their children and share clips with their social networks (Kindberg et al. 2005). In this sense,

remote video coaching technology can now be designed as an extension of the existing behaviour of these parents.

In fact, technology can be used as a medium for support in a way that is suitable for early SLT services, therapists and parents. Parents can practice their role of leading the home therapy, video record interactions with their children and share them with the therapists to access support in the comfort of their own home. Rather than demanding additional clinical appointments or visits, parents and therapists might also engage remotely in either synchronous or asynchronous discussions and coaching sessions. Supporting parents at the early stages of the child's development can enable them to acquire the required speech and language therapy skills, so improving the quality of the early intervention being provided to the child. This approach can thus work towards achieving the aim of the current indirect therapy programmes designed for preschool ages where parents play a central role in the implementation of therapy. By introducing remote support technology, significant support for additional therapy might be reduced along with the associated costs.

This research aims to investigate how remote coaching technology can be designed in a way that is acceptable and feasible with current clinical practice to support parent-led therapy and promote parent-therapist communication. Our study hence contributes to the under-investigated area of HCI and early speech therapy programmes by focusing on the role of parents, exploring and describing in depth the existing practices and challenges of indirect therapy and by proposing an empirically derived design of video coaching technology to improve communication and collaboration. We have thus conducted a broad contextual investigation of support and therapeutic coaching needs. From this starting point, we have proposed a technological design approach to stimulate parent-child interaction for communication skills development and supplement the services offered to parents of children with developmental delays. Our research has also introduced coaching tools used to improve the current relational healthcare model for early speech and language therapy.

The research ultimately contributes to interdisciplinary approaches that combine multiple qualitative design approaches and involve multiple stakeholders (including parents and therapists) in the design process, which incorporates clinical partnership within the home therapy context. This approach has been achieved by utilising, redesigning and innovating co-

design methods that are responsive and specific to the participants, context and research investigation needs.

1.2 Research Aims and Questions

This research aims to 1) explore the existing norms, practices and obstacles to the delivery, adoption and adaptation of home therapy programmes through the lenses of parents and therapists; and 2) investigate design strategies and augment the healthcare system with digital solutions to promote therapy adoption in the children's natural environments and facilitate parent-therapist collaboration. In meeting these aims, the specific research questions are:

- **RQ1:** What are the challenges, opportunities and digital solutions involved in the real-world context of early therapy interventions and parenting children with disabilities?
- **RQ2:** How can the parents of children with disabilities receiving early speech and language therapy inform the design of digital technologies that support parent-delivered therapy?
- **RQ3:** What is the benefit of involving parents in the design process of coaching technologies and how can this inform future healthcare models to support early speech and language therapy?

1.3 Research Approach

In order to understand how technology can play a role in supporting indirect therapy programmes, we have selected a case study approach to observe the therapeutic coaching needs and issues across a number of therapy protocols and with different disorders. This approach has involved two main case studies conducted in collaboration with clinical partners. The first case study (called eSALT) was held in collaboration with Newcastle-upon-Tyne Hospitals NHS Foundation Trust, for children with cerebral palsy, as part of a clinical project funded by the charity SPARKS (Sparks 2018). The second (called ePACT) was conducted in collaboration with the PACT team for the *Parent-mediated social communication therapy for young children with autism* intervention (Green et al. 2010). Both

studies explored the different therapy service delivery models, as well as assessing the design and feasibility of remote coaching systems in different settings.

This research has hence been built on qualitative research methods. Each of the case studies has used a multi-pronged approach (Tomitsch et al. 2018; Cairns & Cox 2008) in order to design a technology to support the parent, both in their interactions with their child and in their communication with the therapist. Each of the studies started with a qualitative investigation and accompanying observation with therapists and parents of the therapy protocols for preschool children. This investigation then led to the design of a mobile video-coaching application for the early therapy through a series of co-design workshops. This approach has been shown to be effective when working with participants to design other digital healthcare technologies (Vines et al. 2013; Wallace, Wright, et al. 2013). In designing engagement activities with the participants, we have been able to develop and assess the design of smartphone applications for each of the case studies. Our research has thus concentrated on designing a coaching technology to support parent-therapist interactions, then analysing the design qualities an effective coaching technique for parents.

1.4 Thesis Structure

In this section, we provide an outline of the thesis with a brief overview of each chapter. The thesis is comprised of eight chapters based on two case studies, with the objective of informing contextual understanding and designing digital technologies capable of addressing the existing support and communication needs of parent-delivered therapy programmes. Summarised in *chapter 1*, we outline how through consideration of these case studies we have produced design consideration recommendations to support early therapy programmes in different contexts with the aim of co-designing them with clinical partners and parents.

Chapter 2 then presents a contextual review of the literature gathered from two domains of healthcare and human-computer interaction. The review focuses on understanding early therapy protocols, family and health coaching theories and concepts, while analysing the role of video interaction guidance in coaching practices. We also draw upon insights from more specific explorations of digital technologies to support children's development and communication, telehealth practices and the various video-based solutions implemented to support clinical or professional assessment. In addition, the chapter reviews the approaches to

design digital solution in this domain and identifies the existing gaps in the literature that this research intends to address.

Chapter 3 introduces the first case study, called eSALT, which focuses on parents of children with cerebral palsy. The chapter explains the study context and the overall methodology, including ethical procedures, recruitment and the design process, before outlining the data collection and analysis approaches. We also provide the study design of the contextual exploration phase, along with the findings from the phase of sensitising the parents' experience along with their needs and values. Finally, the chapter discusses how the outcomes of the first phase informed the subsequent phase and give rise the co-design activities based on the discovery of existing video sharing practices. Hence, the video capture and sharing technologies are perceived to have the potential to deliver the needed support to mothers of children with cerebral palsy and their therapists.

Chapter 4 documents the second phase of the co-design of the eSALT case study with parents and therapists. This chapter first introduces the co-design phase and the design feasibility findings for a remote coaching solution in order to deliver the needed support. The chapter also presents a number of design implications for future video-based digital solutions led by the caregiver to support the mothers of preschool children with special needs. These range from augmenting the current healthcare model with tools to enhancing the communication with health professionals and providing social support. In response to the design principles outlined here, KeepCam is introduced as a smartphone video-coaching technology to support indirect therapy programmes involving parents of preschool children with cerebral palsy.

Chapter 5 describes the final phase of the eSALT case study, dealing with the field deployment of KeepCam in a real-life setting with families and therapists. Here, the clinical partners have designed and delivered a short speech and therapy intervention programme to assess the impact of frequent visits on the child's development, while KeepCam has been deployed to provide support in between therapy visits. The chapter reports on how mobile video coaching tools can be used for continuous engagement with therapy programmes and facilitate social support. In addition, we discuss the opportunities for a responsive model of therapist support for home therapy programmes in which families are more empowered.

Chapter 6 introduces the second case study, called ePACT, for parents of children with autism. The chapter describes the existing therapy protocol that integrates video reflection practices and discusses the overall methodology of the study, including ethical procedures, recruitment, the design process and approaches to data collection and analysis. The chapter also includes the study design of the formative exploration phase, along with the phase findings. Finally, the chapter outlines the experiences learned from the existing therapy protocols and the potential of technology to support self-reflection practices. This approach then highlights the need to inquire further into the required representation of the therapy structure in coaching technology and to co-design a self-directed coaching technology.

Chapter 7 discusses the final two phases of the ePACT case study – namely, the joint co-design activities for the self-coaching technology with the mothers and therapists – and discusses the design considerations related to these technologies. The chapter first introduces the study design of the co-design phase and the design feasibility findings; it then describes the resulting design concepts of a self-directed coaching technology which has led to the creation of the ePACT prototype. The design critique phase and its results are then discussed in order to reflect on the design of the preliminary prototype. Finally, the chapter articulates the outcomes of the co-design study, providing a list of the design elements required for technologies to support parent-led video-feedback technology.

Chapter 8 reflects on the two case studies (eSALT and ePACT) in order to introduce comprehensive design elements principles for coaching technologies whose objective is to support parent-led therapy for children with communication difficulties such as cerebral palsy or autism. In addition, it presents reflections on the adopted design process and approaches alongside issues that arose from the clinical partnership, National Health Service policies and power relations management. This final chapter concludes with a summary of the main research contributions, discussing the limitations and introducing directions for future research.

Chapter 2. Background and Related Work

2.1 Introduction

This chapter reviews the current body of research literature on early speech and language programmes and service delivery techniques, as well as recent digital solutions supporting parent and children's skills development. Overall, this research is built on concepts of health and family coaching, early speech and language delay, and therapy programmes. In this chapter, we aim to explore how early interventions and therapy practices are managed by the caregivers with or without digital means. We also review the digital solutions designed to support telehealth practices and the development tracking of young children, all of which involve data capture and access by the main caregivers.

Throughout this review, we will consider related work from both the healthcare and human-computer interaction literature. The chapter thus begins by describing the early speech and language therapy practices, early-life communication and associated clinical practices. In addition, this opening section describes the challenges associated with parenting children with developmental difficulties, along with the means of support that impact upon the parents' ability to cope and adopt healthcare interventions. The second section then explores how coaching, training, continuous engagement and feedback are typically managed within the family and therapy practices. The objective of this investigation is to provide an understanding of therapy coaching techniques and so highlight both the complexity and the various levels of engagements with healthcare programmes.

In the third section of the chapter, we sample related work from the human-computer interaction and health, in order to present the digital solutions that would facilitate coaching and early speech and language therapy practices. This section specifically outlines digital technologies for therapy service delivery, self-management, development tracking and support for parents at home. The aim here will be to provide an understanding of existing efforts to support early therapy and children development digitally as well as parent-delivered therapy. In the last section, we describe the specific and potential design approaches with parents in the context of early therapy interventions. The chapter then concludes by drawing upon insights taken from the findings to evaluate the commonly-used technologies and design

approaches in early interventions, as well as the design spaces for new technology in relation to this thesis.

2.2 Early-life Communication

2.2.1 *Speech and Language Delay and Interventions*

Speech is defined as the ability to vocalise and produce sounds to talk, while language is the ability to use words and gestures to communicate with others (expressive language) and understand what others say (receptive language) (McLaughlin 2011; Hart & Risley 1995). Recent studies have shown that the prevalence of the rate of speech and language developmental delay in pre-school children in UK is approximately 7 percent (Roulstone et al. 2011; Tomblin et al. 1997; Enderby et al. 2013). At the same time, almost half of children may start school with speech and language difficulties, particularly in socially deprived areas (Locke et al. 2002). The early years of a child's life are critical to his speech and development, while a delay in language development can subsequently affect their social and educational life (Stern et al. 1995; Clegg et al. 2005; Dale et al. 2003).

Children are considered to experience a speech and language delay if they do not meet particular age-related milestones (Hagan et al. 2007; Coplan 1985). These speech and language milestones include babbles or makes gurgling sounds by six months, following commands after one year and combining words by two years of age. Paediatricians assess the development of children during their periodic visits and discuss parents' concerns about their children's speech and language if any exist. Comprehensive developmental assessment and referral to speech and language therapists will be conducted if a children has not meet a speech and language milestone, such as in cases where a toddler does not babble or gesture by the age of 12 months (McLaughlin 2011).

Furthermore, a speech and language delay can be classified into two main categories. There can be said to be primary speech and language delay if no other conditions are found. Then there is secondary speech and language delay if it is associated with other developmental disorders, such as cerebral palsy, autism spectrum disorder or hearing loss (McLaughlin 2011; Bercow 2008). In this sense, the physical and developmental difficulties associated with a

developmental disorder affects the speech and communication skills of the children with a secondary speech and language delay.

For instance, children with cerebral palsy have a neuromotor disorder affecting their cognitive and communication development, which creates additional barriers to the speech development and interventions (Hustad et al. 2012). The communication speed, strength, range and movement required to provide facial expression and gestures can then also be affected, along with speech. A neuromotor disorder complicates the speech and language acquisition process to make it longer compared to neurotypical children (Pennington et al. 2004; Rosenbaum et al. 2007). On the other hand, children with autism have a neurodevelopmental disorder that affects their social, communication, along with restricted and repetitive behaviour and interactions (Burgess et al. 2013; Bailey et al. 1995). The autism spectrum consists of wide range of symptoms and often first manifested in communication and language difficulties. In addition, almost half of the autistic children have intellectual disabilities (Mody & Belliveau 2013).

Moreover, during the early-life of children speech, language and communication skills development are heavily dependent on family and caregivers (McLaughlin 2011; Hart & Risley 1995). For instance, parents communicate with their children from a very early stage by structuring their conversations around language and communication patterns that they can understand, e.g. gurgling sounds, hand waiving, or little words such as ‘yes’ or ‘no’. Researchers have found that parents who interact and communicate repeatedly with their children have impacted positively upon their children’s speech and language development (Hart & Risley 1995; Roulstone et al. 2010). However, children with disabilities often communicate less frequently than other children due their physical or behavioural conditions, giving rise to a significant challenge for parents to promote their children communication skills (Burgess et al. 2013; Bailey et al. 1995; Voorman et al. 2009; Pennington & McConachie 2001). As a result, infrequent interaction and communication can impact their children’s speech and language development.

In addressing both primary and secondary delay, early speech and language therapy (SLT) for preschool children focuses on working with the family to develop the communication skills essential to the children through playing, reading or talking (AAP 2011; Green et al. 2010; Sussman 1999; Manolson 1979). Early SLT constitutes a form of indirect therapy delivered

by trained parents or other caregivers (instead of a therapist). The importance and effectiveness of early therapy have been advocated in the literature to improve children's communication skills before they start school (Majnemer 1998; Pennington et al. 2004; Schmidt & Lee 2005; McLaughlin 2011; Law et al. 2005; Robertsa & Kaiser 2011; Schrader-McMillan et al. 2012) and so reduce the long-term impact of autism (Green et al. 2010; Lord et al. 2005; Rogers & Vismara 2008; Warren et al. 2011). Furthermore, sustainable therapies adoption has been shown to be more effective than short periodical therapy (Law et al. 2005). However, it has also been noted that less clinical attention has been given to the communication, social and behavioural development of children with severe disabilities (e.g. cerebral palsy) compared to the efforts dedicated to their motor development (Hustad et al. 2012; Voorman et al. 2009).

The reality is that in order to apply early SLT, parents need to be trained for home therapy practices. Many of the therapy protocols - such as those outlined by a number of researchers (Eliasson et al. 2011; Gordon et al. 2011; Maas et al. 2008; Aldred et al. 2011; Pepper & Weitzman 2004; Sussman 1999) - coach parents to adopt specific communication practices applicable to their children needs. Consequently, children's communication development can be stimulated and their speech and language difficulties reduced by aiding the parents to adapt their interaction patterns and communication behaviour (McLaughlin 2011).

Hence, parental training focuses on promoting communication in daily interactions by recognising communication signals, responding to them, creating opportunities for interaction and developing new communication strategies that can maximise the potential impacts of the therapy. For example, one of the strategies recommended to promote interactive play is the Observe, Wait, Listen (OWL) technique that reduces the pressure on the child to talk while letting them lead the communication - see Figure 1 (Pepper & Weitzman 2004). In addition to direct coaching and teaching delivered through early SLT, parents are recommended the use of reading resources, such as those proposed by: (Schwartz & Miller 1996; Hamaguchi 2010; ASHA 1925; Barry 2012). These resources can explain speech and language difficulties while suggesting appropriate tools to promote communication.

Figure 1. Example of OWLing speech and language strategy (Pepper & Weitzman 2004)

2.2.2 *Parenthood, Disabilities and Support*

Several studies prominent in the body of research literature highlight the issues facing the parents in raising children with developmental delays, which include the following: high stress levels (Baker-Ericzn et al. 2005; Brobst et al. 2009; Boyd 2002; Oelofsen & Richardson 2006); low adaptation and marital happiness (Higgins et al. 2005; Sen & Yurtsever 2007; Baker-Ericzn et al. 2005); isolation and insecurity due to the lack of information and support (Lord 1984; Solomon & Chung 2012; Sen & Yurtsever 2007; Yantzi et al. 2007); impact on family relationships and employment (Hartley et al. 2010; Sen & Yurtsever 2007; Leiter et al. 2004); risks to caregivers' physical and psychological health (Raina et al. 2005; Brehaut et al. 2004); and being forced to deal with various feelings of anger, denial, depression, anxiety and stigma (Green 2003; Ones et al. 2005; Kearney & Griffin 2001; Landsman 1998; Landsman 2002; Manuel et al. 2003).

Furthermore, the tendency of the mothers of children with disabilities to reduce their social interactions due to complication of the children conditions and stigma has been widely observed (Green 2003; Ones et al. 2005). These studies suggest the impact of low social interaction on mothers' wellbeing and their children's development. On the other hand, a number of studies have revealed the positive impact on the parents' life as a result of effective

caregiving for children with disabilities (Woodgate et al. 2008; Bayat 2007), which includes increasing their resilience, unifying families and utilising resources well to sustain both the individual and the family.

Despite the issues surrounding parenting and children with disabilities, the ability of parents to cope have been demonstrated in previous research in their various approaches. Here, coping strategies involve family and social support, the communication of feeling and needs, access to information, and acceptance resulted from being realistic and optimistic (Manuel et al. 2003; Taanila et al. 2002; Hastings et al. 2005). Moreover, it has been suggested to incorporate social support and consider their psychosocial status in the family-centric early interventions to further promote copying, adaptation and strengthening the family unit (Judge 1998; Ones et al. 2005; Baker-Ericzen et al. 2005; Davis et al. 2010).

The role of professional therapeutic support in coping process and early intervention delivery was shown to be essential to promote the wellbeing of parents and their children, address interrelated issues and provide parents with strategies to develop their child-raising skills (Taanila et al. 2002; King et al. 2004; Solomon & Chung 2012; Sen & Yurtsever 2007; Raina et al. 2005). In addition, it was reported that with the professional support of parents, a better emotional relation could be established with children compared to the resulting depression and stress in parents due to the lack of support (Boyd 2002).

Furthermore, previous studies have highlighted needs and expectations of parents from professional support. These include awareness of available resources and services, comprehension of child conditions, providing instructions and encouragement, understanding expected outcomes, and establishing trusting, effective partnerships with professionals (Redman-bentley 1982; Coffman 1983; Lehr & Lehr 1990; Hornby 2000). While parents have acknowledged the honest and realistic communication of health professionals, to ward off desperation they need even more support to foster hope and optimism towards their family future (Kearney & Griffin 2001).

Early therapy intervention has been demonstrated to play a central role in supporting parents and strengthening their abilities, as well as reducing parental stress resulted from the caregiving responsibilities for children with developmental delays (Voorman et al. 2009). In turn, Trivette et al. (2010) have introduced a family-systems model in discussion of the

impact of early participatory interventions along with the associated support on the parent wellbeing and their realisation of their personal abilities. Consequently, alongside parent-child interaction, child development is positively influenced by a strengthening of parents' skills and recognition of their capabilities (Trivette et al. 2010).

The family-systems model for early interventions consists of four key elements illustrated in Figure 2 (Trivette et al. 2010; Dunst & Trivette 2009). Here the focus is on '*Capacity-Building*' as a crucial element for effective interventions to explain how the therapists engage with the families. The model shows how capacity-building through professional interventions can help the caregivers to identify their needs (i.e. concerns priorities), along with the social support obtainable and the presence of developing or developed abilities (i.e. strengths) serving to address their needs. Hence, significant correlation has been shown between the parents involvements in therapy interventions and their knowledge, skills, beliefs and self-efficacy (Solish & Perry 2008). Accordingly, early interventions have provided a mechanism to support parents and engage them effectively in everyday parenting activities in order to promote their children's development.

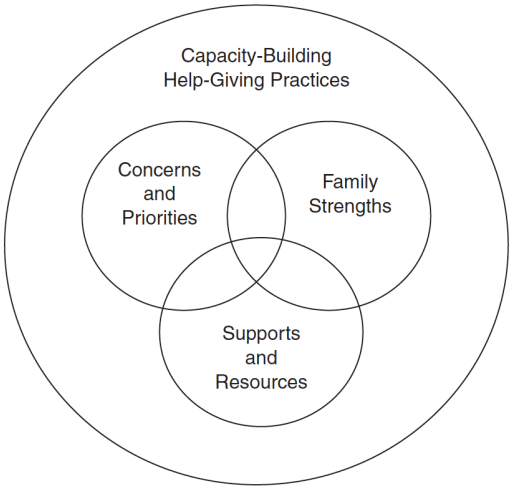


Figure 2. Family-systems model (Trivette et al. 2010)

2.3 Coaching, Engagement and Feedback

Health professionals consider the coaching concept to be a method for promoting behavioural change and improving health outcomes (Friedman et al. 2012). Coaching has also been discussed as a mechanism for early intervention delivery for families of young children with disabilities, centred as it is on notions of family, learner, evidence and self-efficacy (Rush et

al. 2003; Trivette et al. 2010; Passmore et al. 2013). Health coaching has been defined by Olsen (Olsen 2014), as a *"goal-oriented, client-centred partnership that is health-focused and occurs through a process of client enlightenment and empowerment"*. The main coaching characteristics presented in the definition have focused on accomplishing the coachee's goals through a recurring coaching process.

In addition, Allen et al. have nominated the family coach role as one of constituting a strengths-based approach to fostering abilities and achieving these goals, chiefly by stimulating the coachee's confidence, skills and commitment (Allen & Huff 2014). In this way, a sustainable health behavioural change might therefore be promoted by the increased self-efficacy and self-awareness (Bennett et al. 2005; Hecht et al. 2005; Wolever & Eisenberg 2011). Rush et al. consider coaching to be a reciprocal process taking place between the coach and the family, one involving a series of conversations aimed at helping improve the child's life. They have thus identified the following five phases of the coaching process: initiation of specific outcomes; observation or action of existing challenge or new skill; reflection to promote continuous improvements through self-observation; evaluation; and taking a continuation or resolution decision based on the achieved outcomes (Rush et al. 2003).

Furthermore, studies have been conducted of different coaching styles and their impact on the coachee engagement, outlining the following approaches: 1) autocratic or authoritarian coaching where the coach dictates the procedure and goal and controls the coachee's activities with low autonomy spaces provided, 2) democratic or autonomous coaching where the coach guides and shares decisions making and goals setting, providing them with more room of independence and autonomy to lead the coaching process (Amorose & Horn 2000; Syrmpas & Bekiari 2018; Kavussanu et al. 2008). In comparison to autocratic coaching, the coachee perceived that democratic coaching was the more motivating and supportive approach in terms of addressing their personal needs and competence.

In early speech and language therapy, professional therapists have utilised the coaching techniques and principles in home programmes (Baxendale & Hesketh 2009; Green et al. 2010; Aldred et al. 2011). Moreover, participatory therapeutic intervention has focused on strengthening existing capabilities and building new ones to promote parents' self-sustainability and children's development in everyday interactions (Trivette et al. 2010). Allen et al. have also highlighted the fact that families have perceived coaching to be a

therapy delivery model, with coaches seeking to enable their coachees to lead change by offering more awareness in place of education (Allen & Huff 2014).

Moreover, studies have demonstrated the effectiveness of coaching where the number of coaching sessions conducted correlates to the relationship between the coach and the coachee. This collaborative working relationship has been shown to grow with the number of therapy sessions received and so influences the development and self-efficacy of the coachee (Baron & Morin 2009; Kivlighan & Shaughnessy 1995). In addition, as shown in Figure 3, the success of the parents' coaching interventions are shown to depend potentially on the parents' effective engagements in line with the CAPE conceptual model of the parents' engagement in therapy programmes to promote their children's development (Piotrowska et al. 2017). This model is able to define parents' engagement across various levels. It starts from the participants joining intervention programme (connect) through their commitment to therapy sessions (attendance) and active involvement in session-building skills and knowledge (participation) to implementing strategies in their everyday practices with their children (enactment).

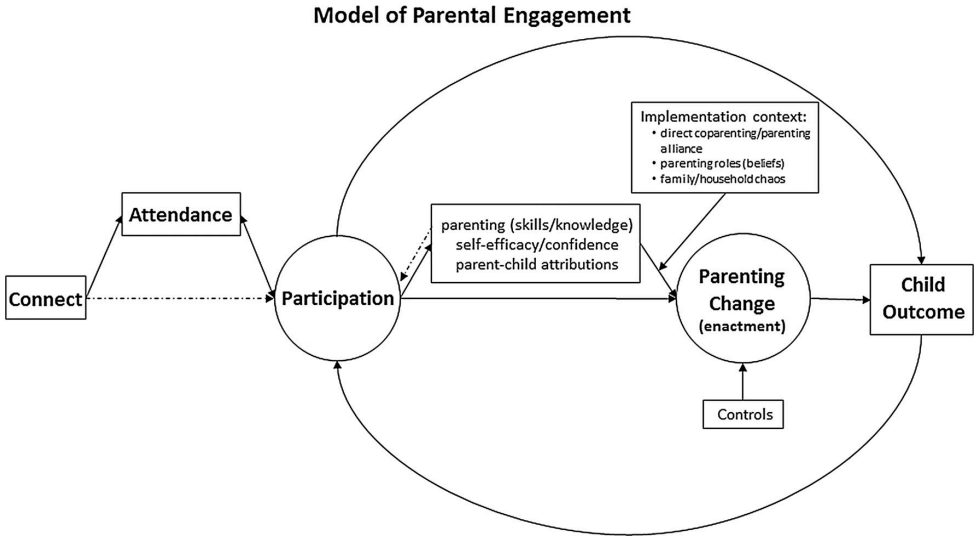


Figure 3. CAPE conceptual model of parental engagement in therapy programmes (Piotrowska et al. 2017)

One established parent-coaching mechanism used to promote the parents' active participation is the use of video feedback (or video interaction guidance) (Kennedy et al. 2011; Balldin et al. 2018; Birbeck et al. 2015). This mechanism has been widely used in parent-child interaction research, where video-recorded interactions are jointly watched by parent and health professionals to observe interaction patterns, provide feedback and identify areas for

improvements (Hustad et al. 2012; Pennington et al. 2003; Fey et al. 2006; Peterson et al. 2005; Pepper & Weitzman 2004; Aldred et al. 2011). The video has been used as a visual tool to guide the therapy discussion by complementing the verbal feedback provided by therapists with visual examples so facilitating the following: creating a focused attention on specific behaviour; providing a memory cue about parent-child interaction; altering parents' perception of themselves and their children; and allowing slow analysis and reflection in order to identify children's communication signals (Fukkink 2008; Fivaz-Depeursinge et al. 2004; Balldin et al. 2018; Fleck & Fitzpatrick 2009).

Furthermore, video recording has provided concrete material proving valuable for professional reflection; video capture has thus been adopted in different contexts as part of the video feedback/guidance intervention (Kennedy et al. 2011; Balldin et al. 2018). For instance, video feedback has been proven useful for clinical visits and for coaching the parents of children with language delay in the Hanen programme (Pennington et al. 2009; Pepper & Weitzman 2004), as well as for pre-school autism communication therapy (Pickles et al. 2016; Green et al. 2010).

The work of Balldin et al. has demonstrated the value of the different video feedback interventions adopted to support parenting and healthy child development, recognising their effectiveness in bringing about positive behavioural changes in parent-child interactions (Balldin et al. 2018). Moreover, studies have revealed promising outcomes of video feedback interventions on parenting attitude, confidence, knowledge and skills which, in turn, improves the quality of parents' interaction with their children (Fukkink 2008; Fivaz-Depeursinge et al. 2004; Nese et al. 2016).

2.4 Technologies for Early Interventions

2.4.1 *Telehealth and Services Delivery*

Direct parent training programmes are challenged by parents' negative perceptions, stress or other barriers to attending the sessions (Hinojosa & Anderson 1991). To face these challenges, McGoron et al. suggest that technology has the potential to augment these programmes with accessibility, motivation and self-directed training elements (McGoron & Ondersma 2015). Indeed, a number of studies have found that parents are using online

materials to access parenting advices (Nieuwboer et al. 2013) and prefer therapy interventions delivered remotely than clinic or home sessions (Tully et al. 2017; Metzler et al. 2012; Hines et al. 2015; Ciccia et al. 2011).

In addition, several studies judge remote coaching programmes to be a widely-used service delivery model; therapy sessions were delivered virtually in these programmes, while additional educational material was provided digitally (Hall & Bierman 2015; Meadan & Daczewitz 2015; Vismara et al. 2013). In fact, the majority of telehealth practices delivering remote therapy sessions start at school age (Keck & Doarn 2014). Different technologies are then used for remote health services, such as videoconferencing, online platforms, and/or mobile devices, either for direct therapy or indirect therapy services delivery (Grogan-Johnson et al. 2010; Ciccia et al. 2011; Wacker et al. 2013).

In fact, numerous studies have used videoconferencing as a mechanism as a service delivery model. It has proven to be acceptable and efficient (i.e. useful to reduce costs and travel time) as well as improving the parents' skills and adoption of practices continuously in their everyday interactions with children (Kelso et al. 2009; Vismara et al. 2012; Mcduffie et al. 2013; Wainer & Ingersoll 2015; Tse et al. 2015). Web-based telerehabilitation programmes can also offer support, consultation, coaching, collaboration and care coordination, which may in turn result in caregivers' capacity building (Nieuwboer et al. 2013; Meadan & Daczewitz 2015; Cason 2011). These studies show that in impacting upon both the parent and the child, online programmes are effective in terms of engaging with behavioural change and enhancing knowledge and skills. However, changes in parents' behaviour are not necessarily the result of increased knowledge (Meadan & Daczewitz 2015).

Compared to conventional therapy sessions, videoconferencing appears to be both reliable and effective to deliver direct speech therapy to children (Grogan-Johnson et al. 2010; Ciccia et al. 2011). However, therapists found understanding and relating therapy to the children's natural environment to be challenging beyond the remote sessions (Grogan-Johnson et al. 2010). Moreover, recent evidence suggests that telehealth is a valid method for professional assessment of speech and language development (Taylor et al. 2014; Waite et al. 2012), while it is also effective for coaching the parents in indirect speech and language therapy (Suess et al. 2014; Snodgrass et al. 2017; Aggarwal et al. 2015; Boisvert & Hall 2014).

Before starting any coaching process, Snodgrass et al. recommend that some preparatory steps should be conducted face-to-face, including identifying targets, strategies and procedures (Snodgrass et al. 2017). In addition, other forms of technology were used – such as discussion forums and mobile devices – as supplementary elements to increase the parents' engagement, strengthen support and expand contact time with therapists and other caregivers (Hall & Bierman 2015; Isaki & Farrell 2015).

Furthermore, DuPaul et al. have explored the use of online training courses as a mechanism to deliver parent training; such training has proven effective in reducing the symptoms of young children with attention deficit/hyperactivity disorder (DuPaul et al. 2017). In comparison with the face-to-face parent-training programme, the study showed that both delivery models were associated with high levels of engagement, knowledge acquisition, adoption and behavioural development. Researchers have also compared the efficacy of online training courses with and without therapists' support. Their analysis reveals that therapist-assisted training increases parents' commitment and heightened perceptions of their children's capabilities and needs, while improving the children's social skills as well as the acceptability of intervention (Ingersoll et al. 2016; Pickard et al. 2016; Ingersoll & Berger 2015). Additionally, Sanders et al. reported that online self-directed interventions represent cost-effective solutions to improve parenting skills and children behavioural development without reliance on health professionals (Sanders et al. 2014). However, compared to the therapist assisted solutions, improvements seemed minimal in terms of parent-child interactions and perceptions of the child abilities in self-directed solutions (Ingersoll et al. 2016).

In addition to the values of telehealth to access health services, Amir et al. have highlighted the need to facilitate collaboration and integration of healthcare plans of the diverse team of caregivers and health professionals working with children with complex conditions in order to improve coordination and developmental outcomes (Amir et al. 2015). Other related works report the impact of integrated information technologies on treatment' discussions and collaborative decision-making which influences the quality of therapy positively (Kientz et al. 2006; Kientz et al. 2005).

While internet-based peer support interventions has been recognised as a supplementary support channel to professional support which revealed the parents' self-management abilities, peer support can now be accessed by the parents through social media to seek

information, parenting advices and emotional support. Consequently, in comparison to offline support, online peer support has been shown to have a positive impact on parents' skills and wellbeing and reduced judgment and anxiety (Yarosh et al. 2016; Ammari et al. 2014; Niela-Vilén et al. 2014). In contrast, a study by Sarkar et al. notes that caregivers are increasingly using online health information to access knowledge and support, which consequently affect their mental health negatively (Sarkar et al. 2016). Moreover, Huh et al. have observed video blogs posted by patients intending to share and learn from their personal experiences, concluding that such activity leads to intimate connection between peers and improvements to their mental health (Huh et al. 2014).

Although teletherapy and online interventions have been shown to be feasible, effective and capable of expanding the reach of health services, they have only been adopted slowly by health professional and healthcare services providers due to the inadequacy of infrastructure, lack of telehealth standards or training and negative therapists' perceptions about telepractice (Hines et al. 2015; Gardner et al. 2015; Keck & Doarn 2014)

2.4.2 *Communication and Behaviour Development*

Several digital technologies have been used to augment rehabilitation therapy. Keck et al. discuss the importance of technology in the diagnosis and treatment of behaviour and communication disorders, noting that clinicians and therapists have been slow to utilise technologies to improve therapy outcomes (Keck & Doarn 2014). For instance, Kientz et al. have reported the use of digital technologies to support children with autism. Their study shows that digital technologies have been beneficial for in-clinic session use in helping therapists to make better treatment decisions and share data between therapists working with the child, as well as helping children to communicate their needs through wearable devices (Kientz, Hayes, et al. 2007).

A wide set of digital solutions have thus been developed to support clinicians and therapists in therapeutic practices; they have led to improvements in children's motivation, social skills, speech intelligibility, speech elicitation and vocabulary building, so helping them to develop new patterns of communications (Hailpern et al. 2012; Hamidi & Baljko 2014; Fell et al. 2004). For example, Hailpern et al. have demonstrated the efficiency of augmenting clinical environment with audio and visual cues which encouraged vocalisations of children with autism (Hailpern et al. 2009). Meanwhile, the MagicLand project has promoted the child-

therapist relationship, proving the abilities of interactive and collaborative table-top technologies to facilitate communication of children with Attention Deficit Hyperactivity Disorder (Pykhtina et al. 2012a; Pykhtina et al. 2012b).

Chien et al. (2015) have studied another related system, which they take to demonstrate the positive impact of visually assistive communication and mobile applications on children and therapists. Here, children with autism were more motivated to learn and communicate with others, while the therapists were able to save time, effort and easily create or adapt their therapeutic methods (Chien et al. 2015). Indeed, one of the common and powerful approaches to encourage children with speech delay to produce more speech and assure intelligibility is through gamification. For instance, a turtle race game has been used by therapists to train the children to regulate the speech rate and intelligibility (Hoque et al. 2009).

Fernandes et al. have reported an increased use of mobile devices, such as Augmentative and Alternative Communication (AAC) tools or equivalent applications, to collaborate with parents and set up therapeutic tasks (Fernandes 2011; Wadhwa & Jianxiong 2013). Here, several attempts have been made to design AAC solutions that can facilitate independent interaction of children with development difficulties in their natural environments (Benton et al. 2012; Jones 2004). For instance, an augmented reality assistive technology called MOSOCO has enhanced the quality and quantity of communication and social interactions of children with autism in the school setting (Escobedo et al. 2012). Another digital solution called PixTalk has also allowed the children with limited communication abilities to use smartphone applications to access and communicate using images to express their needs and emotions (Leo et al. 2011). The study found that PixTalk can be used to expand the therapy practices in natural environment, yet it can be challenged by the training needs and cost.

Moreover, AAC tools and assistive technologies now demonstrate their benefits to children with children with cerebral palsy who experience a range of speech and language difficulties. Most commonly, AAC is used as a high-tech or low-tech communication aid - such as in eye tracking, sign systems and in speech machines - to support face-to-face interactions, enhanced expressive communication and increased understanding of language (Clarke & Price 2012; Andersen et al. 2010). These assistive devices have improved children's communication skills while reducing the burden on families, although many of the possessed devices are not used by the families. Therefore, further comprehensive studies were required to understand and

identify the family, child and therapy needs to support the beneficial use of AAC solutions (ØSTENSJØ et al. 2005).

In addition to the use of assistive technologies to facilitate communication and develop the children's skills either in therapy session or real-world, video-based solutions have been employed by professionals to enable therapy assessment, diagnosis and training. Hayes et al. have proposed CareLog as a fixed video capture system controlled by a remote trigger to provide functional behavioural assessment for children with severe behavioural disabilities. The study has indicated many benefits, including easier capture and enhanced assessment, with minimal impact on therapists' workloads (Hayes et al. 2008).

Another selective video capture has been introduced by Nazneen et al., who used the flagged moments (using a wireless remote) in the continuous camera recording for behavioural assessment of children with autism (Nazneen, Rozga, et al. 2012). The study verified the benefits of behaviour analysis based on examples from the children's natural environments and reinforced the importance of promoting the parents' roles in their children's therapy interventions. Furthermore, video modelling techniques have been introduced for adolescents with autism and they have been proven to help youths with autism to learn necessary communication and behavioural skills by watching a peer video for imitation or reviewing their own videos (Custodio 2016; Ulgado et al. 2013).

Prior studies have placed greater emphasis on supporting therapists and clinicians in the direct therapeutic interventions or the delivery of the indirect therapy sessions with a limited attention on how to support the parents beyond therapy sessions. Talkbetter is one of the remarkable solutions to support parents' adoption of the therapy guidelines in their daily interaction with their children (Hwang et al. 2014). Talkbetter is a real-time linguistic analysis system designed to help parents' in the integration of training guidelines at home by analysing speech and providing in-the-moment guidelines accordingly. Although the system has had a number of voice detection issues that needed to be addressed, an evaluation has demonstrated high levels of parental engagement with the system.

Similarly, much as children language development is based on their interaction with parents, LENA has been developed to improve parent-child communication at home for children with language delay. LENA (Language ENvironment Analysis) is a commercial speech assessment

tool that provides conversation monitoring, direct instruction, reminders as well as educational materials (LENA 2018). The automatic language assessment requires the children to wear audio recorders in order to monitor their speech and provide meta-linguistic analysis feedback to parents through the associated application. LENA hence provides statistical information to parents, such as number of spoken words from the parent, the duration of child's vocalisation and turn counting between the parent and the child.

Although the current system has been effective for children with primary speech and language delay in the home setting, researchers have revealed some concerns when the system was used with preschool children with autism (Dykstra et al. 2013). For instance, data accuracy is lower than anticipated due to some characteristics associated with the children condition, such as high vocalisation. Moreover, additional information, such as vocalisation intention and nonverbal cues and gestures from the parent or the child, cannot be captured even though they are considered an integral part for the assessment of communication development. Therefore, the study suggests using observation-based tools with video capture element for accurate identification of different communications patterns for children with disabilities.

2.4.3 *Tracking and Caregivers Support*

A variety of digital technologies have been proposed to monitor neurotypical children's development and support communication between parents and paediatricians, while facilitating information sharing between and for parents (Balaam et al. 2013; Le Dantec et al. 2011). Gibson & Hanson have argued that different forms of digital technologies play a central role of support for new mothers. In particular, they suggest that mobile devices and social media are beneficial for new mothers in various ways, including searching for information while on the move, relaxation or entertainment during or after night feed time and connecting with similar families for support (Gibson & Hanson 2013). Recognising the importance of development tracking and giving feedback to paediatricians, Kientz et al. (Kientz, Arriaga, et al. 2007) have indeed explored the use of digital technologies to record developmental milestones electronically and share them with paediatricians. Their study has suggested either using the personal records captured by the parents, or automatically tracking activities with wireless sensor-enabled toys.

Video-based record-keeping technologies have been introduced in various ways to support therapy and data capture practices. Several technologies have been developed for tracking the

development of young children, but they have focused more on record keeping than on providing remote support (Kientz & Abowd 2009; Kientz et al. 2009; Hayes et al. 2014; Kientz, Arriaga, et al. 2007). For instance, KidCam was based on a semi-mobile video-based record keeping device that stores continuous recording for a limited duration (Kientz & Abowd 2009); it demonstrated that families with a history of developmental delay were willing to use video and photo technologies for tracking.

Moreover, BabySteps have explored the barriers to record-keeping, memory-making and communication during the children development, which has included parents' busyness, forgetfulness and unwillingness to share information with their paediatricians or public health systems. Thus, to promote better record-keeping by parents, the use of online sharing, recording photos or videos and integrating reminders were proposed (Kientz et al. 2009; Suh et al. 2014). Although these studies reported increased parents' confidence for tracking their children development, there have been some limitations including the availability and appropriate adjustment of the mobile capture device as well as their limited storage. The study suggest that the use of such devices are now accessible as they are portable and can be easily set up in fixed locations.

A similar solution, Estrellita, has been used by parents of preterm infants for record keeping and remote support (Hayes et al. 2011; Hayes et al. 2014). In addition to record keeping, Estrellita also seeks to promote better communication with healthcare professionals (Hayes et al. 2014; Tang et al. 2012) and social interactions with peers, family members and friends (Liu et al. 2011). Studies of its use indicate that parents' awareness improves and that supportive feedback increases their confidence. However, while parents have benefitted from Estrellita, researchers have also found that requirement of data capture has constituted a significant burden on their existing responsibilities.

Alternative strategies for developmental data tracking have been explored by Vonach et al. The study explored the value of monitoring children health in the home context through the MediCubes project, where health data was gathered in a playful way using toys (Vonach et al. 2016). Collecting health data from the children's natural environment without health professional presence reduces the children's anxiety and provides more time for clinicians' assessment, which in turn leads to better diagnosis. Park et al. have explored the role of technology in supporting parents in communicating medication adherence information to

health professionals and improve the quality of medical care for their children (Park et al. 2008). Due to the parents' hectic lives which have affected their adherence to medical programmes and the professionals need to efficiently use clinic session, ENSURE has been designed to automate the capture of medical data and facilitate parent-professional communication. The study suggested that different caregivers, locations and times must be considered when designing digital solutions to support parents at home.

Most recently, Kollenburg et al. have investigated how different healthcare professionals perceive the development data tracked by parents using the uGrow mobile app (Kollenburg et al. 2018). As a parent-tracked child data solution, uGrow allows parents to support their children development by providing advice and assurance about their children development based on the data entered manually by parents or automatically through connected devices such as child monitor. Research found that different personalities and types of professionals have different data needs, yet the open nature of the tracked data has allowed them to use it in accordance with their needs, while the videos have helped them to understand the context of each family and personalise advice.

A number of efforts have investigated the impact development tracking and support on the parents of children with developmental difficulties. Marcu et al. (Marcu & Hayes 2010; Marcu et al. 2012) have discussed the use of SenseCam, a wearable digital camera designed for non-verbal children with autism to capture interactions automatically from the child's perspective. The technology here is found to improve the communication between the caregivers and their children, due to a better understanding of the children's needs. However, data capture using a camera was identified as intrusive for others. In addition, SenseCam provides continuous video capture without showing the child or the full context which are needed for behavioural assessment (Grogan-Johnson et al. 2010).

Concerns about data capture have been investigated in the Experience Buffers project, where the capture technology embedded in the children natural environment and store data when triggered by the caregiver. Consequently, the study suggests that evidence of behaviour can be easily integrated with the electronically tracked development data for the diagnosis and treatments of children with autism (Hayes et al. 2005). However, further investigation has been required to assess the parents' ability to capture problem behaviours with or without previous training. Similarly, Nazneen et al. have assessed parents' ability to track and capture

their children's problem behaviour using CRAFT, home embedded cameras for continuous recording and flagging. Their study has proved the potential and validity of the parents' collected data in the home setting to provide examples of the children's behaviour for clinical assessments. As a result, CRAFT demonstrate an effective solution for clinical observation which reduces the cost of direct observation and the possibilities to affect natural interactions (Nazneen, Rozga, et al. 2012; Nazneen, Boujarwah, et al. 2012).

Pina et al. have suggested a mobile-phone delivered interventions for parents of children with Attention Deficit Hyperactivity, called ParentGuardian, which delivers therapy strategies that are automatically triggered by high stress level during daily activities through worn sensors. Although the study shows the potential of mobile guidance to increase adherence to therapy strategies, further investigation is required to explore the accuracy of detection methods and practicality of embedding technology in therapy programmes (Pina et al. 2014). Furthermore, caregiving activities may affect the health and wellbeing of informal caregivers of children with disabilities, so increasing their physical, social and emotional stress levels (Chen et al. 2013). The immersive nature of caregiving, coupled with the efforts of caregivers to balance their personal responsibilities, impacts upon the caregivers' overall life. Chen et al. therefore propose that digital solutions should be considered to support and alleviate the burden on caregivers.

2.5 Co-design and Parent-Delivered Therapy

Use-context influences the design of digital technologies where stakeholders are considered experts in their context. In this sense, human-computer interaction design practices have a long history of engaging stakeholders as participants in the design process; this can be attributed to their expertise which can impact positively upon the resulted design for potentially sustainable technology adoption (Simonsen & Robertson 2013). In turn, methodological approaches to user-centred and participatory design help to establish common understandings between the designers and stakeholders about the use-context and surrounding experiences before the technology is actually designed (Ehn 2008; Muller 2001; Peter Wright & McCarthy 2010).

Several design methods have been employed in user-centred and participatory approaches to involve the participates in the process actively, thereby eliciting their needs or establishing a

common language with designers. These methods may, for instance, include contextual inquiry through interviews and questionnaires, design probes, mock-ups, scenarios and/or collaborative design workshops. These design methods can be employed iteratively throughout the co-design process (Muller 2003; Spinuzzi 2005; Sanders et al. 2010; Tomitsch et al. 2018). This process thus represents a cooperative relationship and partnership that can be established between designers and participants throughout the development lifecycle; here, either the designers join the participants' world (e.g. ethnography methods) or the participants join the designers' world (e.g. low-tech prototyping methods) (Muller et al. 1997; Muller 2001; Steen 2013).

Several studies have discussed the values of a co-design process in different contexts. Steen et al. (2011) have discussed three dimensions of services co-design benefits, which involve the designers, participants and service providers (Steen et al. 2011). For the designers, the co-design process can improve the ideation process and result in a better definition of participants needs. For the participants, it results in services that fit their needs and facilitate cooperation between participants and services providers for more innovation on an organisational level. However, research has enforced the need to align the design services goals carefully to enjoy the benefits of co-design methods, while avoiding any associated costs and risks of not achieving these benefits. In addition, a number of studies have found that benefits of co-design methods start from the production process where the designers conduct knowledge gathering and develop an empathic understanding of the participants while designing their methods (Lee 2014; Mattelmäk 2008; Wallace, McCarthy, et al. 2013).

In the context of indirect interventions, parents play a crucial role in effective therapy delivery within their natural environments. Technologies designed in this context should build on the parent-delivered therapy approach and facilitate their access to knowledge from healthcare professionals, as well as meeting their support needs. Previous studies advocate the importance of engaging parents in the design of healthcare in order to improve qualities of services (Gustavsson et al. 2015; Gustavsson 2014; Årsand & Demiris 2008). While it is clear that parents' engagement in the design process is vital to improving their adherence to indirect therapy in the real context, the parents have received less attention compared to other stakeholders - i.e. clinicians and therapists - where the design has been driven by a focus on services delivery and assessments (Vismara et al. 2012; Hall & Bierman 2015). In addition, there is a lack of discussion about the use of co-design approaches within the early therapy

community which might be the result of the complexities of families' lives (i.e. raising preschool children with developmental delays) (Brehaut et al. 2004; Hastings et al. 2005) which, in turn, may affect the families' engagement in the design process or make it very slow.

The majority of research within the context of parent-delivered therapy has focused on remote services therapy for clinical trials in order to evaluate the effectiveness of self-directed or therapists-assisted coaching solutions (Snodgrass et al. 2017; Kelso et al. 2009; Ingersoll & Berger 2015). These solutions have been designed or re-appropriated by clinicians or designers, such as designing web-based and digital educational material (Nieuwboer et al. 2013; Cason 2011; Vismara et al. 2013) or using videoconferencing tools like Skype (Kelso et al. 2009; Mcduffie et al. 2013; Wainer & Ingersoll 2015; Aggarwal et al. 2015). Hence, the limited discussions of co-design and participatory design approaches within this community have resulted from their consideration to support therapy delivery and clinical setting where the approaches to design have been done differently. However, the interaction design has not necessarily considered the engagement of the caregivers within the process of service design.

Moreover, several design studies for the healthcare and development monitoring domain have described the process of balancing the clinicians and caregivers needs throughout the design of clinical data captured from natural environments beyond clinics, such as the caregivers' home. Most of these studies have focused on facilitating the integration of digital solutions in the caregivers' environment in order to support professional data access (Liu et al. 2011; Nazneen, Rozga, et al. 2012). For instance, Tang et al. have adopted a hybrid design approach with families and healthcare professionals to understand data capture and access needs, while designing digital solutions to track the development of premature infants (Tang et al. 2012). The authors started with used user-centred approach and have conducted interviews with the parents in various settings, whether at home or in hospital, and with individuals or in pairs. The healthcare professionals themselves were interviewed in groups or as individuals, with a focus on how the data collected by parents can benefit clinical practices.

The authors then applied participatory design activities with healthcare professionals to develop the required solution (Tang et al. 2012). These design activities have included card sorting, low-tech and high-tech prototyping. The authors argued that the parents were not involved in the design sessions due to the significant time required for these sessions and the

limited availability of parents with premature infant due to their caregiving responsibilities. However, they have recognised that the healthcare professionals have had several years of experience and knowledge of these families; hence, they have also been able to provide insights from the families' perspectives.

This team of researchers examined the challenges of data capture using smartphones infants in an additional related study for designing clinical data capture solutions for parents with premature (Tang et al. 2011). They hence conducted a comparative study between the use of clinical forms and the use of mobile application for exercises tracking and communication of relevant information with clinicians and research team. The results highlighted both the practicality and the challenges of data capture using smartphones. The researchers followed these primary findings with semi-structured interviews with parents and clinicians for further exploration.

Furthermore, an in-depth formative study has also been conducted by Kientz, Arriaga, et al. to understand the record needs for tracking the progress of children's developments (Kientz, Arriaga, et al. 2007). The study involved multiple stakeholders including new parents, experienced parents, other caregivers (nanny or family members) and clinicians. Here, the authors chose to make semi-structured interviews with the parents (either individual and group) and focus groups with the clinicians. The study suggested that focus groups were easier to arrange with clinicians due to their limited time.

Another study has been based on formative understanding outcomes (Kientz, Arriaga, et al. 2007), this time following an iterative design approach to evaluate the effectiveness of mobile data capture and access prototype in real settings (Kientz & Abowd 2009). Before deployment, the parents were interviewed to understand their existing practice and data capture and access of their children. These interviews were then followed by an evaluation of low-fidelity prototype for three months with four families to ensure that the design fit the families' needs. Families were also interviewed in the middle of the deployment period to collect the data from the devices and understand their current use. The study concluded with a final interview describing their use behaviours and suggesting improvements.

In addressing designs for the in-home health management of children by their caregiver, Park et al.'s study outlined a clear user research process (Park et al. 2008). The process involved

several design activities, such as in-home contextual inquiry and cultural probes, paediatrician interviews, a participatory design workshop with the parents, design generation and needs validation using concepts storyboards. This study focused on solutions for in-home managements for use by parents; the design process thus prioritised engaging with the parents and understanding their perspective.

In their research, Nazneen, Boujarwah et al. have outlined the methods used for design concepts exploration and concepts validation with multiple stakeholders to design a support system for parents of children with problem behaviours (Nazneen, Boujarwah, et al. 2012). Here, the exploration of related concepts included two studies: 1) a first study aiming to understand the daily experiences and behavioural data capture practices, involving field observation and interviews conducted in children's schools, autism treatment and general healthcare centres and hospitals, and 2) a second study aiming to understand the stakeholders' data capture needs through separate focus groups for parents, teaching assistants, clinicians and a mixed group with other parents/educators/clinicians. These phases informed the design concepts generated to represent the relevant needs within a context then used as a basis for the prototype design. The prototype used for the concept evaluation study was based on usability testing in a lab setting alongside multiple stakeholders and with in-home deployment. The authors reported that the exploration and validation studies allowed them to understand the subtle needs and nuanced expectations of different stakeholders about capture technologies, so providing recommendations for future designers.

Other studies described the methods used to support participation in the evaluation process. For example, Marcu et al. presented the evaluation of families' individual experiences using a wearable camera for therapeutic interventions (Marcu et al. 2012; Marcu & Hayes 2010). The authors employed weekly semi-structured interviews in which the families described their experiences and the accompanying images were analysed. The authors concluded that the observational data enables the discovery and the creative use of associated challenges. Pina et al. have worked with parents of children with attention deficit hyperactivity disorder to evaluate a mobile application designed to promote their adherence to therapy practices (Pina et al. 2014). The authors describe the process as a partnership with parents, which started with individual design feedback sessions and was then followed by two-week deployment (i.e. one week based on hourly triggered notifications, and one week with wearable wrist sensors). Finally, the author used rating questionnaires to assess the usefulness of the technology. The

authors highlighted the design challenges for the parents of children with developmental difficulties which could be attributed to the stress they felt from the demands of caregiving and other responsibilities.

The study conducted by Hwang et al. is then described the engagement of parents of children with speech and language delays in the design process for indirect therapy programmes (Hwang et al. 2014). The authors took an extensive field study approach with therapists and parents designing in-home mobile intervention prompts for language delays. Here, the design process consisted of three stages: 1) initial studies with therapists involving consultations and interviews to learn the relevant therapeutic practices, as well as staging discussions with parents to understand the challenges they face in these practices, 2) a study of service concepts involving interviews with the parents and scenario videos for initial design feedback, and finally, 3) prototype evaluation with parents where the resulted intervention reminders were reviewed with therapists. The authors stressed that the design was both clinically-driven and highly motivated.

Although these studies have described the engagement and methods used in the design process which resulted into generation of design requirements that fits parental and/or professional needs, they involved at best only limited reflection on the benefits or the difficulties faced during the design process. In contrast, one interesting study described an creative design method built on ‘data-enabled design approach’ to explore the value of children’s data capture and track in the home setting for the interaction between parents and healthcare professionals (Kollenburg et al. 2018; Bogers, Kollenburg, Rutjes, et al. 2018). Here, the authors built a ‘Data-enabled Canvas’ which was then deployed for five families and three healthcare professionals in a real-life context for a situated exploration. The canvas combines various tools including sensors, physical prototypes and digital prototypes to understand data use along with related experiences and behaviours.

The deployment started with minimal data in the canvas; when gauging the participants’ insights during the deployment, the canvas then changed remotely to enable continuous exploration. At the end of the deployment, this process resulted in a different canvas for individual families based on their use. The authors discussed the value of data-enabled design method where the data became a creative material during the design process and resulted in a detailed personal exploration from the real context and holistic insights on both experiential

and behavioural data. Therefore, the authors argued for dynamic design methods to identify the data capture, sharing needs and facing the challenges of understanding data-collecting needs within ecosystems (Bogers, Kollenburg, Deckers, et al. 2018).

Another participatory design project reflected on the participants' feeling of ownership through employment of a language aid toy designed for children with autism (Rijn & Stappers 2008). The participants in this co-design process included the children, their parents and care professionals; participants were involved in the contextual exploration and prototype evaluation process. Throughout the design process, the study identified three sources of motives to promote the sense of participants' ownership of the design process and the associated results. These motives are instrumental (e.g. support self-expression), perceptive (e.g. allow them retain expressions), and symbolic (e.g. acknowledgment). Finally, the researchers here argued that the sense of ownership can evoke the participants' motivation and engagement in the design process.

A study conducted by Marshall et al. then discussed the impact of engagement in the design process on the participants wellbeing (Marshall et al. 2014). The authors described the construction of a method to establish conversations with the participant for contextual inquires, which might involve collecting photographs, videos and/or the creation of design probes. The production process was thought to have a positive impact upon the design discussions between the participants and designers to establish better contextual understanding. Here the researchers argued for the need for careful consideration when adopting the making methods as part of the design process due to their possible effect on the participants' wellbeing (i.e. enjoyable or overwhelming), especially amongst the participants who had concern for wellbeing.

Gustavsson et al. have reviewed the experiences of parents with specific involvement through two experience-centred co-design studies in paediatric care (Gustavsson et al. 2015). Within this context, the authors remarked upon a dominant role of healthcare professional in the care co-design process, along with an underestimation of the parents' abilities to contribute in design quality. They also argued that the quality of the co-creation process was the result of a collaboration between healthcare professionals and parents, which should include both the healthcare tasks and the parents' context. Moreover, user-centred design were perceived positively in the design for healthcare domain, with the solutions having the potential to

improve the participants' health as a result of their engagement in the design process (Moody 2015).

However, some challenges remain arising from the involvement of multiple stakeholders in the design process for healthcare. These challenges include the following stages: ethical approval; participant recruitment; maintaining engagement; adapting methods to meet healthcare constraints; the contextual inquiry of sensitive and personal data; demand for time and resources; establishment of a common language between disciplines to communicate the design ideas, and planning evaluation methods that balance the discipline's requirements. In conclusion then, Moody (2015) has argued for the need to develop appropriate strategies and design approaches for healthcare to reduce these challenges (Moody 2015).

2.6 Summary

This chapter has provided a background overview of the context around early speech and language delay and the difficulties facing the caregivers (i.e. parents, teachers, therapists) in terms of raising children with developmental delays, traditional health services delivery methods and the associated digital support techniques. We have also described the coaching practices and techniques that influence the early therapy delivery methods and subsequently impacts upon the parents' skills and the children development. We sampled related work from human-computer interaction and digital health communities in order to consider in particular how they would support coaching, parenting and children development for indirect therapy. Within this context then, various digital solutions have been discussed in the name of supporting remote service delivery, communication and social skills development and tracking either by parents or health professionals.

Indirect therapy programmes have placed a great emphasis on improving parental knowledge and behaviour which, in turn, have helped develop and enhance children's communication skills. The engagement of parents was considered a key element for effective early therapy outcomes and the implementation of practices in daily interactions with their children. Engagement with early intervention starts from session attendance and continues up to the integration of therapy routines. The most recent digital solutions have largely focused on monitoring child development, utilising technology within therapy sessions, or delivering remote therapy sessions. While the usage of data capture and share has been demonstrated to

support assessment, reflection and monitoring of children's interactions, most solutions are targeted at health professionals or approaches to child development.

However, as noted above, early speech and language programmes depend heavily on parents and are driven by them in their real settings. In contrast, support for home therapy practices has received relatively little attention compared to digital support for children of school age who are receiving direct therapy. Moreover, home-based therapy has been considered an additional burden on parents' caregiving responsibilities for their children with developmental difficulties. In this sense, the role of technology in the support of the indirect-therapy practices of parents still needs to be explored further, along with analysis of the collaboration of parents with health professionals and members of their social networks. At the same time, computer-supported cooperative solutions in the healthcare context can play a valuable role in facilitating and strengthening parent-professional collaboration and parent-led therapy practices, in which they can personalise treatments, increase motivation and integrate goals (Chung et al. 2016; Mentis et al. 2017).

This chapter has thus provided insights for the thesis and research goals, where we have been able to extend our investigation of the process of speech and language coaching for parents of children with autism and cerebral palsy, while exploring the challenges of self-management, therapy integration, and digital solutions use. Prior research has focused on effective support from the perspectives of health professional services to facilitate data capture and access or therapeutic knowledge dissemination. However, the real experiences and needs to promote adherence to the indirect therapy practice of speech and language setting has not yet been fully explored from the parents' side of therapy practice. Our approach has therefore been to focus on the potential to design digital solutions driven by the parents' nonclinical needs for their daily therapeutic and caregiving routines; these should then be balanced with the therapists needs and healthcare services constraints. Throughout this research, we have aimed to bridge the gap in the literature by adopting the co-design approaches to explore and design digital solutions that fit the needs of experiences of the parents of preschool children with disabilities in the context of programmes of indirect therapy.

In this chapter, we have also presented a variety of human-computer interaction literature discussing the co-design methodologies in various contexts and with various stakeholders. These methodologies have been useful for both contextual understanding along with design

generation and evaluation. In considering the relevant design studies, we have also reflected on the challenges of participants engagements throughout the design process, the impact of methods used on the participants and the design challenges apparent within the context of healthcare service.

However, the context of indirect SLT therapy has to contend with the complexity of care-giving responsibilities towards pre-school children with special needs, along with the issue of parents experiencing fatigue and stress (Baker-Ericzn et al. 2005; Brobst et al. 2009; Boyd 2002; Oelofsen & Richardson 2006). These problems can be combined with the challenges of design in healthcare context with multiple stakeholders (Moody 2015; Gustavsson et al. 2015; Chen et al. 2013). Hence, in the course of this thesis, we have developed design processes to engage this community with a careful configuration of the design methods to manage the challenges imposed by the context. Through the design process, we have learnt about therapeutic practises, studied the needs of parents and therapist, generated in-depth contextual insights, informed the design of digital tool, mitigated the dominance of clinicians' roles and promoted parents' sense of ownership to drive the design process for their own therapy practice needs. The following chapters will describe the design process and specifics of the design methods employed in each of the case studies presented in this thesis. Our aim will be to analyse the needs of therapeutic coaching and observe the issues arising across a number of therapy protocols and with regard to different disorders.

Chapter 3. Understanding the Indirect Therapy Needs

3.1 Introduction

This chapter introduces the first case study for designing technologies to support home therapy programmes for parents of children with Cerebral Palsy (CP). CP is a permanent neurodevelopmental disorder which starts in early childhood and affects a child's development (Rosenbaum et al. 2007). It is estimated that each year, 1,800 preschool children are diagnosed with CP in the UK (McFarland 2018) and up to 1,500 children in the USA (Stern 2018). There are approximately 2 to 2.5 CP cases per 1000 births worldwide (HealthGrades Inc 2018). Due to brain injury occurring before, during or after birth, children with CP have difficulties controlling their muscles. During the early stages of childhood, a child with CP can encounter developmental difficulties relating to their vision, speech, feeding, mobility, behaviour and learning (McFarland 2018). These early childhood difficulties can lead to a child's exclusion from social and educational activities (Schmidt & Lee 2005). In response, the National Health Service (NHS) provides clinical therapy interventions to support parents and promote the development of preschool children with CP before they enter school. Majnemer (Majnemer 1998) has demonstrated the importance of early clinical interventions to address developmental difficulties before delays manifest. Therapy services for preschool children are primarily home-based. The parents' role is fundamental at the preschool age as the home is the first learning environment for the child where the parents need to promote the child's skills on a daily basis. Therefore, home-delivered therapy helps in understanding the environment in which children are raised and in establishing the importance of the parents' role in their development (Majnemer 1998).

One of the most common developmental delays encountered relates to speech and language (Shong & Cheng 2007). Approximately 22% of children with CP have limited speech intelligibility and up to 30% have no functional speech, which can affect their social interactions (Pennington et al. 2017). As such, therapists typically support parents of preschool children through early Speech and Language Therapy (SLT); also called *home programmes*, *indirect therapy* or *parent-delivered therapy*. Early SLT often helps children with disabilities to develop their communication skills before they reach school age (Majnemer 1998; Diggle & McConachie 2009; Pennington et al. 2004). In the UK, the

amount of therapy that families receive varies greatly, and therapy visits can be infrequent (Watson & Pennington 2015). A clinical investigation of parent-delivered therapy for occupational and physical therapy revealed that parents often felt overwhelmed, and struggled to properly deliver such programmes (Hinojosa 1990; Hinojosa & Anderson 1991). While a number of digital technologies have been proposed for tracking developmental delay (Hayes et al. 2014; Hwang et al. 2014; Kientz & Abowd 2009; Kientz et al. 2009), it remains unclear if they are appropriate to support therapy approaches with preschool children.

In this case study, we collaborated with one of the ongoing clinical projects held in the Institute of Health and Society at Newcastle University. The project aims to assess the feasibility and acceptability of designing a frequent therapy delivery model supported by technology to promote parent-child communication skills. Our role in this project was to focus on designing suitable technology to support the existing therapy practices and to respond to the contextual challenges facing the parents in adopting the therapy programme. The case study was pursued in collaboration with Newcastle upon Tyne Hospitals NHS Foundation Trust, and funded by the SPARKS charity (Sparks 2018). This case study consists of two phases for qualitative investigation with mothers of children with CP and speech therapists in the United Kingdom. The aim of these phases was to engage in contextual and design dialogues with the mothers and therapist in order to understand their needs and co-design suitable solutions. This was then followed by generating the design goals and field deployment of the resulting technology.

In this chapter, we introduce the overall methodology of the CP case study and describe the first phase of contextual inquiries. The first phase was focused on understanding the context of parenting children with CP, existing social communication patterns, and the current home therapy practices. The aim of this phase was to establish a formative understanding of the support and empowerment needs of mothers and explore the therapists' experiences, to identify indicators for potential technology design that can be used to improve existing practices. From this was derived the second design phase that is explained in detail in Chapter 4, along with the resulting technology design. Finally, the field deployment study is presented in Chapter 5.

3.2 Methodology

3.2.1 *Ethical Approval*

The CP case study involved a series of design activities and deployments with parents and therapists who were experienced with home therapy programmes from multiple National Health Service (NHS) trusts. Thus, the case study was approved by the external research ethics committee (National Research Ethics Service – NRES) established by the Health Research Authority of NHS for Newcastle and North Tyneside. Then, to work with participants from the NHS, the researcher successfully completed a series of four courses required by the NHS, which introduced Good Clinical Practice (GCP), UK Regulations, and Research Governance Framework requirements for trials and studies conducted with the NHS. Moreover, based on the research interests and activities, which required direct contact with participants from the NHS, we established the need to obtain an NHS Research Passport (RP). This RP was granted for the purpose of gaining the required comprehension and knowledge of therapy practices to support the study and afforded us access to the clinical facilities and participants' homes when needed. We had to provide all the required documents to satisfy the requirements of the full RP application. This included obtaining a Disclosure and Barring Service (DBS) check certificate and an occupational health clearance certificate, as well as completing a curriculum vitae, role assessment, and RP application form. An RP letter of access for research was received, which confirmed our right of access to conduct research through the NHS Foundation Trust for the purpose of this study. After receiving the confirmation letter, we had to apply for and be issued a non-trust-staff identity card, which then allowed us to start conducting the research. Furthermore, in order to conduct the observation activities at the participants' homes, we had to submit and follow the guidance of the risk assessment form provided by Newcastle University Safety Office.

During this case study, the invited participants were given a verbal and written information sheet to explain the overall research aim, the participant's role, collected information, forms of the data captured (audio recording or photos), research phases from design to deployment, expected outcomes, and the data protection measures. Participation was voluntary, and it was explained that they could withdraw from the study at any time without needing to give a reason, and that any information collected would be deleted. Participants were assured that their decision to reject the invitation or withdraw from the study would not affect any services that they were currently receiving or might receive in the future. All participants received a

copy of the information sheet, along with a consent form to complete, sign, and return before or during the first research visit.

3.2.2 *Participants and Recruitment*

The aim of the case study was to establish an understanding of the home therapy practices and the challenges of infrequent therapists' visits, then design and deploy the required technology to augment the current therapy process as a response to the established contextual understanding. Thus, we required participants to have experience with indirect therapy programmes, basic technology literacy, and be willing to take part in this study. In order to establish a comprehensive overview of existing home therapy practices and potential digital solutions, we aimed to involve all relevant stakeholders, including speech therapists and parents. The recruitment process was facilitated through the Institute of Health and Society at Newcastle University. Therapists were recruited to the study through the existing network of the Institute of Health and Society. The therapists then acted as gatekeepers; via their local networks, they recruited families they thought would be interested in joining the study.

Despite the pressures facing mothers as the main carers for children with CP, and the high dropout rate (up to 77%) from parent training programmes (Hinojosa 1990; McGoron & Ondersma 2015), we managed to recruit eight mothers of children with CP and four speech and language therapists for the extended design activities through NHS Foundation Trusts. The target participants were the parents as they are the main carers and receivers of the home therapy service. While we were open to working with either the mothers or fathers of CP children, all the carers in the recruited families were mothers.

All the mothers had experience with home therapy programmes and working with multidisciplinary professional teams since the developmental delay had been identified, even before receiving a specific CP diagnosis. Unfortunately, one of the mothers had to drop out during the study due to demanding medical care responsibilities: all their data has been deleted. Table 1 summarises the demographic data of the seven families. The mothers were from three different cities in the North East of England. All of the mothers were experienced with home therapy programmes, and their children had been diagnosed with CP when between 6 and 37 months old. Three of the mothers were working part-time, while the rest were full-time carers at home. Five mothers were living with their partners who were working full-time; the other two mothers were separated. Four of the parents (mothers and fathers)

held undergraduate degrees, three parents held postgraduate degrees (two Masters and one PhD), while three parents had only completed secondary school; the remaining four parents left school before completion.

The therapists were domain experts working with preschool children with special needs with ten to fifteen years of experience. They worked in two different NHS trusts in the North East of England. Three of the therapists were practising indirect therapy based on home visits, while one therapist worked with inpatients.

ID	Mother Age	Mother Employment	Partner Employment	Child with CP (Ages in months)			Siblings (Ages)
				Gender	Age	Age at Diagnosis	
C01	37	Stay at home	FT job	M	35	25	Sister (18), Brother (11), Twin Brother
C02	38	Business Owner	FT job	M	39	37	None
C03	28	Stay at home	NA (Separated)	F	24	18	None
C04	37	PT job	FT job	F	27	12	Brother (7), Sister (5)
C05	33	Stay at home	NA (Separated)	M	13	12	Brother (9)
C06	29	Stay at home	FT job	F	19	12	Sister (15), Brother (14), Sister (6)
C07	37	PT job	FT job	M	28	06	None

Table 1. Profiles of mothers of children with CP and their families – Ages are in years

3.2.3 *Design Process, Data Collection and Analysis*

The design process of the CP case study involved three main stages for design and field deployment, as depicted in Figure 4. The first design phase (contextual inquiry phase) was focused on contextual exploration through observations and interviews. The aim of the contextual inquiry phase is to understand the existing challenges and digital practices in the real-world context of early therapy interventions and parenting children with disabilities (covered in this chapter). This was then followed in the second phase (co-design phase) by a series of design activities and workshops designed based on the contextual exploration results and aimed at investigating the feasibility of integrating new or existing technologies to deliver support in this context (covered in Chapter 4). The results of the co-design phase informed the design activities of the following phase and helped to identify new directions to be explored in the next phase. Throughout the case study, the research team would meet after each session

to discuss their thoughts, identify recurrent concepts and any new directions to be explored in the following workshop. The findings from the design phases derived the final system design and development, as explained in Chapter 4. This was then deployed in the final stage, where the participants critically reflected on their experience of using the designed technology in real therapy practices (covered in Chapter 5).

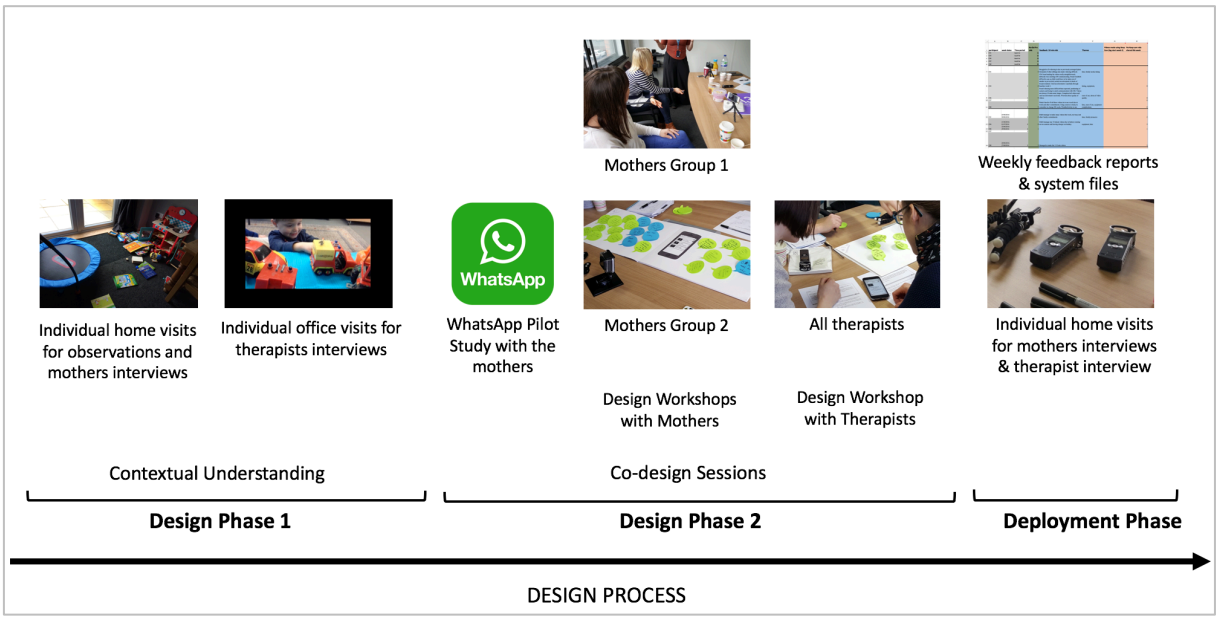


Figure 4. eSALT design process

A triangulation approach was applied in each phase of the design process, so that data collected from various sources (therapists and mothers) and by various methods (interviews, observations, video sharing) were collated for sensemaking (Yardley 2000). The data collection was performed following the prescribed data collection protocols of the institutional and national health ethics boards (UK). Each of the sessions were audio recorded, transcribed and anonymised. The design study led to the collection of 21 hours of audio recording for the individual interviews and workshop sessions, which were all transcribed, along with 70 observation photographs collected from the home visits, and 18 shared videos from the pilot study (min. duration 14 seconds, max. duration 4 minutes). The deployment study led to the collection of around 6 hours of audio recording from the individual interviews, which were all transcribed; along with 5 log files of conversation messages (exported from the system with the participants' permission), weekly feedback reports, and 147 shared videos (min. duration 11 seconds, max. duration 120 seconds).

Qualitative analysis using inductive thematic coding was conducted on the resulting interview and workshop transcripts (Fereday & Muir-Cochrane 2006). The transcripts were examined line by line to allow open and low-level codes to emerge without any underlying theory. The data reached saturation by the fourth participant interview. Initial codes were then compared and combined when overlapping discussion was identified between therapists and mothers, along with relevant material from the phase activities (such as reports and conversation texts). Codes were clustered together into recurrent and high-level themes; these themes were then described by quoted data. Themes were then incorporated according to high-level categories and listed in the phase findings. The codes and themes were discussed and refined iteratively with the research team.

Furthermore, we also collected media files (photographs and videos) that were shared by the mothers during the design or deployment phase, along with photographs taken during the home visits. The video files were also analysed using inductive content analysis (Mayring 2004). The videos were coded and examined against specific attributes; including the equipment used, home setting, environment perception, self-perception, child reactions to camera, play context, other carers' involvement, and suitability for therapy review. Moreover, during the analysis process of each phase, the results of the discussions during the interviews or workshop sessions were combined and compared with the results of the content analysis, where common and conflicting findings were identified.

3.3 Phase 1: Study Design

The aim of the initial phase in this case study was to establish an understanding of the real-world context of parent-delivered therapy programmes and parenting children with CP. This phase was undertaken to explore current practices of communication and therapy delivery, experiences and feelings, challenges and needs, digital technology use, and opportunities for improvements. The phase aim was achieved through open-ended semi-structured interviews and observations that were conducted individually with mothers and therapists.

All the mothers were visited in their homes, while the therapists were visited in their campus offices. Interview and observation sessions lasted around 60 minutes (with therapists) and 90 minutes (with mothers). Through interviews and observations, we explored the mothers' and therapists' experiences of healthcare and home therapy programmes. The mothers were asked

about their daily caregiving routines and activities; their concerns relating to parent-delivered therapy, support and communication strategies with the various professionals; and their current social media and digital practices. Additionally, with their consent, we observed the family homes and captured photographs of spaces and objects that the mothers discussed or showed to us during the visits. These included therapy instruction notes, home adaptations and equipment (to accommodate additional child needs), and media shared with other carers. Examples of the observed materials are shown in Figure 5, including the equipment used to facilitate the integration of therapy practices into daily routines by the mothers and other carers.

Therapist interview sessions focused on understanding their current working routines and practices, the issues they experience with home programmes, and the types of support and communication strategies they use with other professionals and mothers. A deeper insight into social support and parent-therapist communication practices resulted from this phase, as described in the following section. The outcomes were used to structure the discussions and plan the activities of the next phase, which focused on designing digital solutions, driven by the existing practices and needs. See Appendix A for the interview guides.

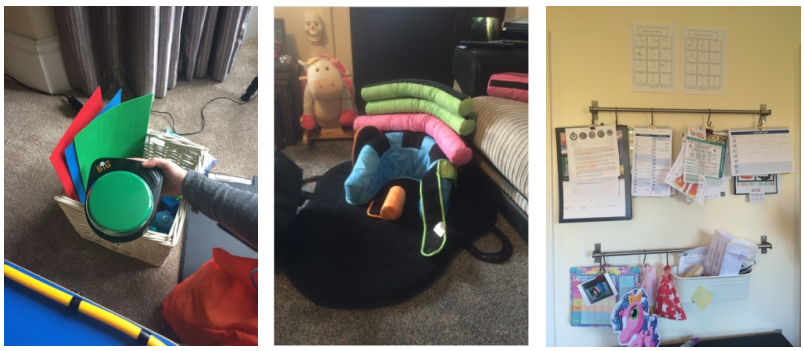


Figure 5. Observations from family homes: "BIGmack" button (left); child support and exercise chair (centre); sign language sheet hanging in the dining room (right).

3.4 Phase 1: Contextual Findings

The results revealed four main areas of challenge, relating to motherhood of children with CP, home therapy delivery, social support networks, and current communication and digital practices. In addition to the special care demand, we found that the mothers of children with CP had to engage with multiple home therapy programmes and numerous specialists as a result of the combined conditions associated with CP, such as physical and speech delays. The results provided a broad view that covered the different communication channels and support

needs facing the mothers while interacting with the various therapists and carers, without focusing on a single type of therapy delivery or social contact. In this section, we report the major themes of each of the four challenging areas of the informative understanding of the context; which reflect mothers' and therapists' perspectives.

3.4.1 *Motherhood and the Challenges of Disability*

Adapting to a New Life Routine

The mothers all emphasised the fundamental change in their lives resulting from having a child with special needs. In general, the mothers found changes in the ways in which they viewed and experienced life, due to the demanding special care routines for children with CP compared to their other children. For example, one of the mothers said: *"Being a mum and your child has got problems with talking, it is not something that is natural, like being a mother comes naturally. It has actually dramatically changed a lot of things. Having [the child] has massively changed myself, my own outlook on life. Everything has changed. I used to work full-time. I used to – I suppose – be quite selfish in a way. You can become put in this position and your whole world changes and is turned upside down, basically."* [C01]

Most of the mothers indicated that the change in their lives was due to their commitment to many therapy visits from the different specialised therapists for each of the conditions diagnosed in their children. This was considered an additional commitment facing the mothers, in addition to the distinct and demanding daily care routine for children with CP. For instance, CO5 said, *"We do have a lot of appointments, more than I have done in the past with the other children."* In order for the mothers to handle their children's needs and commit to therapy visits, some of them either changed their jobs to part-time (n = 2), took long leaves (n = 1), or just quit (n = 2). Likewise, three of the mothers said that they had less time for their other family or personal responsibilities, as C06 explained:

"It is like sometimes I feel like I have got to be a speech therapist, a physiotherapist, I have got to be all of these things, as well as a mum of four and a house cleaner. You have got to be self-motivated … I have got loads of ideas of how to help her. I was like, "Ah". My head was exploding. I only have so much time. I have got to try and get all of this into the time. Just, honestly, my head was mashed."

Additionally, all of the mothers described their experience of denial when they realised that there was a problem, followed by a period of hope resulting from the fact that doctors could not provide an exact diagnosis of CP until later in the child's development. Yet, four of the mothers said that they were stronger in accepting the reality compared to other family members. Most of the mothers said that the demanding care routines and the process of waiting for development helped them to cope. As the mothers explained:

"I think it is probably something that you just gradually realise as time is going on that things are not quite right, and he is probably going to have longer-term needs." [C07]

"I think it is just the fact that I have to look after [the child] that keeps me just getting on with it really." [C04]

Do It Yourself

All of the mothers mentioned that they were the main carers of their children and they were doing everything by themselves, as C01 said: *"I do most of it myself really."* The mothers' responsibilities included looking after their children's needs, tracking development, learning from different therapists, and ensuring that other carers implemented what the mothers learned. Moreover, the mothers stated that their children were very dependent and demanding of physical and emotional support from them, even during therapy visits. They felt that they knew their children's attitudes, strengths and behaviours better than other carers, and found this understanding to be helpful for interacting with the child properly and for their collaboration with the therapists to promote their children's development skills:

"He knows what you are talking about. He knows what is on the telly. If you turn it over to a different channel he does not like it. In that way he is quite clever. If he has finished with a drink he twists his face. If he wants something he will look and cry for it. He is good at communicating in sort of I know what he wants and what he does not want." [C05]

The therapists (n = 3) also confirmed the importance of the parents' role with preschool children in promoting the parents' independence and improving the whole learning environment for the children. For instance, one of the therapists said, "*One hour a week with me is not going to make that difference. I need to impart that knowledge to you and those skills to you so you can be doing that effectively all of the time. Get grandma in, get dad in, that kind of thing."* [T02]

Furthermore, all mothers found themselves attending the therapy visits alone, learning all the time, and trying to turn every activity with their child into an opportunity to support their development. Yet they expressed a need to engage with other carers and to use the child's achievements to encourage other family members to get involved. As C01 said, "*Then for me to try and teach another person is extremely difficult. I feel like I should be recording everything and playing it back to other people."* Some of the mothers (n = 5) placed the physiotherapy programmes, sign language sheets and therapy devices in various areas of their houses, as a way to engage other carers and siblings (see Figure 5).

Learning and Self-Discovery

Most of the mothers expressed an eagerness to learn and explore new techniques to support their children's development. Some of them were currently exploring online resources (n = 4) or consulting with other family members (n = 2) to learn more about CP, alternative solutions used by similar families, mobile applications or suitable toys to promote the children's development. For instance, C02 said: *"I am just googling and reading up on things. How people are trying to improve? What speech do? I google a lot when I am free to find out what I can do to help and for general knowledge. But I take that with a pinch of salt, because I understand that there are so many things on the Internet, and everyone's severity is different; but it is just to give me some degree of information, that is all."*

Moreover, three mothers had invented techniques to support their children's development based on the child's interests; for example, using online videos or Siri as playful communication tools, or using YouTube videos and other applications to promote language development. Other mothers (n = 2) developed their own solutions to support their children's independence; for example, transforming a wooden tray with wheels into a movement tray to support the child's mobility at home (see Figure 6). However, two mothers described their fears of exploring online resources, given the amount of discouraging information about their children's diagnosis; yet they were still eager to learn from specific resources when recommended by others. As C04 explained:

"I realise how specific [the child] situation is. I am cautious about finding stuff that is really relevant to us, and also I do not want to know if the future is not what we want. I looked at the Internet a lot when she was first diagnosed, and it was terrifying. Maybe that was a good

thing, to help me prepare. If somebody recommended me a really good website or something then I would be really pleased. That would be great, either with therapy ideas."

Figure 6. Invented movement tray from IKEA (left),
and communication aids arranged at the child level (middle, right)

Uncertainty and Fear of the Future

Different children with CP have different developmental delays. The mothers were aware that their children would have developmental difficulties from birth, but that the specific diagnosis would be ascertained only as the child developed. Thus, some of the mothers (n = 4) reported the difficulty of waiting for the diagnosis, as C03 said: *"It was hard at first, hearing the words, but I already knew. It just lifted a weight off my mind. I was always wanting to know what I am dealing with, what I need to do, what I do not need to do. Am I making it worse by trying to make her walk, trying to make her crawl and things like that?"* Additionally, there was a reported variation in the professional support received by each of the mothers, and some of the mothers expressed their uncertainty about the available services for children with CP at each stage. For instance, C04 commented, *"There should be more information available about stuff and services that is out there."*

The therapists described the challenge of communicating developmental expectations to the mothers due to their awareness level or high expectations. Thus, the therapists expressed the need for interpersonal skills to understand the parents and to be realistic in communicating information at the right time. Both mothers (n = 5) and therapists (n = 4) said that they focused on short-term goals when discussing expectations and progress. As they said:

"I often get out the building blocks of communication and kind of visually talk through – this is what we are doing and this is what we need to do to get there, because often they will say: 'Oh, when do you think they will talk?'" [T02]

"I tend not to look too far into the future because you just do not know what is going to happen, unfortunately. I find that if you start to look long term I can get myself really stressed out imagining what is going to happen, when really if you take one day at a time it is far easier. I just take every day as it comes." [C01]

3.4.2 *Delivering the Indirect Therapy*

Seeing the Big Picture

Due to various developmental delays faced by children with CP, their professional team consists of a number of specialists, such as physiotherapists, occupational therapists, and speech and language therapists. The professional team tends to visit the children in their real environment (i.e. home) to learn more about the parent-child needs and plan suitable therapy practices. While all of the mothers acknowledged their appreciation of the vast range of information and expertise that was on hand, they also remarked on the challenges of working with a large team of professionals, specifically the sheer number of therapy activities to do with their child. For example, C06 explained:

"I did not really know what to do without their guidance. I suppose from them coming in, has shown me and made me understand that children like [my child] need constant therapist kind of input. Just fitting it into all your daily routine. But at the end, it is me who has to do all of that work, which is great, but I sometimes think, 'How am I going to do all of this?' You know, they give you all these programmes, it is a lot of work!"

The mothers were able to establish an overview of the care goals and recognise the overlapping roles of these practices. In an attempt to cope with the volume of practices, they began to integrate multiple practices into single play sessions, as C03 said: *"So there may be slightly different things that Portage want me to do but may involve a bit of the physio movements that the physio wants [the child] to be doing. It is a lot of work, but because you are doing this and also doing a bit of physio or singing songs – so, it makes it a little bit easier because you are doing two or three things that people are asking you to do at the same time."*

However, some of the mothers (n = 6) found it difficult to maintain a big-picture view of the goals while also being the main caregiver, as C04 expressed: *"At the same time, I think it just*

amazes me how vague the whole thing is, about what they expect, about where they are heading, about what they are going to do to get there. I just think it is all just really vague."

The mothers discussed the challenge of prioritising practices and addressing each of the child's development issues. This can sometimes mean making tough decisions to progress in one area at the expense of another, such us focusing on weight and feeding issues more than on communication skills. The therapists also have a share in this struggle. As one of the therapists (T01) explained, in each visit, they try to balance their discussions between multiple developmental aspects, including feeding, communication and education: *"You have to go to see them with two hats on to figure the communication and the feeding and often you have to solve the feeding first and then you have to say – 'Right, now I cannot come back for another three weeks to talk to you about communication.'"* As a result, some of the mothers (n = 4) described the visit sessions as sometimes hectic with multiple discussions, adding that they had to rely on other professionals or social groups to seek answers to their questions (which might better have been answered by the therapists).

Visit Frequency and Child Wellbeing

In addition to regular home visits by therapists, most of the mothers (n = 6) emphasised the need for ongoing contact between visits and defining good routines with their children that engaged them in as much therapy as possible. However, from the mother's perspective, there are several challenges to establishing this support system. The primary one is the difficulty of having no fixed schedule, as visits are organised based on the child's progress, parent learning style, and support needs. Furthermore, there was a controversial discussion around the frequency of visits, with most of the mothers (n = 4) insisting they needed more frequent visits from the therapists; they cited that the long interval between visits meant that they often forgot the practices, had concerns about the child's progress, and felt the need for reassurance. Moreover, they noted that therapists who visited more frequently had a better understanding of the child's health situation. For example, C07 explained that *"You could have more contact with them and more assistance from them, and maybe not always waiting until you have the next visit to be able to get in touch, to just get a pointer to say, 'Am I doing the right thing here?'"*

The therapists discussed the parents' demand for more therapy sessions, as T04 said: *"People thinking that more speech therapy is going to make everything better!"* The therapists stressed the importance of the parent role for continuous practices and responses to the children's cues to promote their skills. Moreover, some therapists (n = 2) confirmed that the therapy visits were used to motivate the mothers and point out the achievements.

The challenge of visit frequency is made worse due to the organisational constraints on the therapists; they have predefined working hours in which they can arrange visits according to their geographical location. Therapists often find themselves rushing between places with strict time allocations per visit. This is combined with the reality of working with children who experience health issues, moods, or tiredness during visits, which can make it extremely difficult to complete everything within the allotted time. The mothers and therapists discussed how mothers sometimes video recorded their interactions with their children and showed them to the therapists during the visits, as evidence of achievement or to consult a therapist about the struggles they were facing in interacting with their children. Therapists (n = 3) found these videos useful, as they led to more discussions about practices and helped them to reflect on and assess the child's progress. For example, the participants explained:

"We had a problem when [the child] was really unhappy in the car so I videoed her and then I sent the email to the consultant and stuff like that." [C04]

"Because of smartphones, people do take videos, and show us occasionally video clips of something they have done, especially if they are really proud of something the child has done, which is effective." [T03]

Commitment vs. Forgetfulness

Prior to the first home visit, the mothers expressed significant uncertainty as to the role of the therapists, levels of support services, and the expected therapy impact. As C06 explained, *"I suppose, in the beginning, I kind of thought that they would come out and do a lot more than they do. But then I realised that actually, no, they are there to teach me to do it on a daily basis. I never expected anyone to come in every day and do my job."* For the therapists, the first visit is exploratory: the first opportunity for them to learn about the family and their needs, and most importantly to set expectations and establish the flexible support plan. Recognising that each family is unique, the therapists adapt their therapy approaches based on the child's needs and the mother's learning style. Additionally, the practices are based on play

activities and are introduced by the therapists through demonstration, explanation, and coaching techniques.

In addition to supporting the child's development, the training sessions are designed to promote the parents' confidence, help them identify the priorities, and upskill them to the point where they only require monitoring from the therapist. This confidence was recognised in some of the mothers (n = 4), who explained how they use the learned knowledge during the visits and tailor the strategies to better suit them. Additionally, the mothers learned the importance of being persistent in the practices for the child's development and to overcome the challenges of the child's mood, wellbeing, and other life responsibilities. For example, one of the mothers said: *"I do try to do a little bit of everything every day. In the bath we tend to sing songs, so he gets a little bit of that. You cannot expect to be doing an hour of a certain routine. It is not working that way."* [C01] Moreover, the therapists (n = 3) confirmed that they found the mothers committed to the therapy practices when they understand them better, with therapists observing and re-teaching when needed, as T03 said: *"I think sometimes people will take it on board in the first session, and then other times it takes a lot longer to drip-feed it again, and you have to give that message on more than one occasion."*

Due to the demands arising from the parents' circumstances, most of the mothers described how they struggled with forgetfulness: finding themselves forgetting some of the practices they should be doing, and scheduling overlapping appointments with therapists. For example, C07 explained, *"If I am going to remember it all then I kind of need something to go back to. I sometimes have made notes about what I would do, which is very teacher-y of me."* Three of the therapists suggested that the forgetfulness was made worse by the lack of other forms of communication, with most information only being communicated verbally to the mothers, as T03 said: *"We do that verbally with parents, but we do not have written or pictures or evidence of other ways to communicate to the parents. So, I do feel like a lot of things might get given to the parent verbally, but probably get lost in all the other stuff that they are dealing with."*

Lack of Progress and Frustration

While all of the mothers said that they enjoyed doing the practices, they found it frustrating when they could not get their child's attention or if the practices conflicted with a difficult development issue they were facing. As C03 explained, *"I say to the therapist, well it is all*

right, you are a therapist, you have got many years' experience. I cannot do it, I cannot force her. But sometimes you just get on with it." This in turn can lead to a lack of progress in the child's development, further adding to the frustration. The large investment of time spent doing the practices and the lack of progress caused a number of mothers (n = 2) to lose their enthusiasm, while others (n = 4) were able to remain motivated regardless of whether they noticed any progress. As C06 commented: *"[The child] has made quite – well, massive progress to me to where she was even six months ago. But it is still very, very slow."*

Two mothers went on to suggest that the progress was sometimes invisible to them because they saw the child constantly. On the other hand, all the therapists confirmed that development progress will plateau, and they try to encourage the mothers by having them reflect on their earlier achievements and defined goals. For instance, T02 explained: *"Just having to talk to them about the plateau and again, going through notes and say: "Look, you know from this, from September to December, you made this bit of progress, he was responding really nicely and you know from now until then, we have not much progress and we just need to keep on going because it is likely taking time."*

Furthermore, the therapists plan for small steps towards meeting outcomes and are careful to manage the parents' expectations of progress and avoid frustration. While some of the mothers (n = 3) confirmed that importance of target setting as a way to celebrate achievements, they felt unfortunate due to the small achievable targets for children with CP or undesirable expectations of their children's development.

3.4.3 *Social Support and Communication Practices*

Family Support

Families played a central role in supporting the mothers in several ways; including support from the father, siblings, or extended family members. Emotional support often came from the partner or grandmother. Also, the majority of the mothers (n = 6) received physical support from their families: looking after the child and being involved in the therapy practices. As C03 explained: *"I think my nana is a really good factor in my life at the minute with [the child]. When my nana's not here anymore I will panic. I will not know what to do, I really will not."* Other mothers (n = 2) discussed support for the practices through exchanging conversational videos of the child with other families' children to promote the child's

communication skills. Two of the mothers had family members with specialised medical knowledge who were able to give supportive medical advice and reassurance. As C02 commented:

"My family members, I will say, 'Look, this is the problem.' So, they will read up and say, 'Look, there has been other cases like this or like this.' I am not like a science person or biology person. I just live a very basic life, you know. So, things like that my family are good with, so they will tell when I express that I am concerned about this and this."

Most of the mothers (n = 5) described the limited levels of support they received from their partners due to their partners' long working hours. Four of the mothers discussed the difficulties arising from their families' involvement, which included the child's preference for the mother, difficulty in sharing practices updates, rare joint visits with family members, and busyness with work and life commitments. Through home visits and sharing practices, the mothers found themselves learning from the professionals and playing a reverse role with their families as they became the experts. Different within-family sharing practices, and motivations for sharing, were apparent, including sharing to teach other family members about the practices (n = 5), sharing the child's achievements for encouragement (n = 3), sharing the medical updates (n = 3), and looking for reassurance (n = 2). The mothers (n = 4) also described the difficulties they experienced sharing their feelings and development expectations, as C05 noted: *"We share lots of stuff, but I think there is some stuff where you just think it is like opening a can of worms and it is too difficult."*

Peer Support

One of the changes noticed in the life of the mothers of CP was in their social life, as C02 expressed: *"I do not know, I have shut off now ... I have not got a time and I do not want to either. I spend my time with my son."* As explained by the mothers, this was due to limited time and lost flexibility due to the childcare responsibilities (n = 5); having new or different interests compared to their old friends, due to the child's condition (n = 3); and having less desire to share their child's condition with others (n = 2).

Some therapists (n = 3) and mothers (n = 4) confirmed the importance of peer emotional support from other families of children with CP. As one of the mothers said, *"It is quite comforting really to see that you are not alone because I think when you have had no*

experience of it, you think everything that is happening for you alone." [C07]. The mothers (n = 2) found it a relief to talk to similar families, as they knew exactly what they were going through. In addition, there are different kinds of sharing between peers, including sharing experiences around diagnosis, therapy, therapists, services, and medications. The mothers found it easy to meet peer families through social and therapy playgroups, except for three mothers who found it hard to find families with CP children in their community. Some of the mothers (n = 2) discussed how this communication was extended outside the social groups' boundaries, either through text messages or Facebook Messenger. As C04 explained: *"Some of the people we have met through groups, I could just text them, or messenger them on Facebook and ask their advice."* However, mothers and therapists said that there were barriers and limitations for peer families' communication. These were due to the stress from hearing other stories (n = 2), and comparing the children's conditions and development (n = 5).

Professional Support

Mothers of preschool children with CP have several contacts amongst different professionals to track their child's health condition and development progress. These include paediatricians, dieticians, health visitors, speech and language therapists, occupational health, physiotherapists, and early education programme staff (known as portage). Home therapy support starts with referral and extends to when a child starts at school. Similar visits at nursery and community centres are carried out when needed to train the other carers. The mothers discussed receiving paper-based practice guidance, as well as equipment and toys for children with special needs to find suitable support for the child's development (examples are shown in Figure 7).

Different sharing practices between the professionals were identified, including the multidisciplinary team meeting, as C01 explained: *"We all sit down and we go over what we want to improve in the month, what has improved, and look towards what we are going to do."* Some of the mothers (n = 2) mentioned that these meetings were arranged according to need and suffered from poor attendance by the professionals, yet they found it helpful to share the child's updates with all professional carers at once. Three of the therapists said that they were making joint home visits with other therapists. Two therapists also mentioned that parents found these meetings and visits helpful in that they did not have to repeat a story to each professional in turn. Additionally, therapists collaborate with the more regular service

providers, like portage, to support the parents between the scheduled home visits. For instance, T01 commented: *"We work really closely with our portage staff and make sure that we spend time supporting them because they often see children more regularly than we would. So, if you can put time into supporting them, then they can then equally support the parents as well."* Therapists also reported that professionals' sharing practices helped them discuss family and child needs, provide feedback to other professionals, and integrate therapy plans and shared goals.

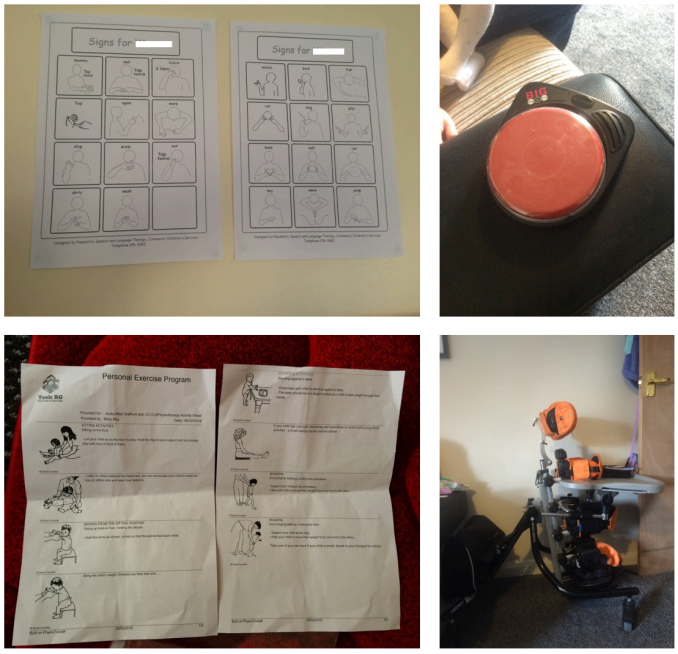


Figure 7. Guidance sheets, equipment, and toys received by the mothers

In addition to therapy delivery, therapists (n = 3) found that mothers used these visits as a form of stress relief and that the visits allowed them to share their emotions and concerns, seek advice for support services, or discuss their personal issues. The therapists (n = 3) found these discussions helpful to better understand the parents' practices, provide better services, and learn from the parents' experiences; as T02 said: *"I think that sometimes it is useful because it makes you think – 'Oh yes, I have not thought about that or I have not heard about that.' Different ideas and things like that."* However, three of the mothers mentioned the challenge of visit arrangements, as C07 said: *"My speech therapist worked the same days that I did, so we had a bit of difficulty trying to get appointments."*

Mothers and therapists discussed limitations to the professional support available, due to the limited time and large clinical caseloads. Moreover, all the mothers had contacted the

therapists through phone calls or email, as C04 said: *"We had a problem when [the child] was really unhappy in the car, so I videoed her and then I sent the email to the consultant. That has not been encouraged from them. That is me finding their email address and going – 'You need to see this email.' [Laughter]"* Another mother discussed the use of a formal sharing system by a nursery to share reports and media about her child's developmental progress: *"They have got an online thing called Orbit, so every day they put pictures or videos up. So even though I am not there, I know I can see he has been feeding, playing, laughing. So, I know he loves school and learning there." [C02]*

3.4.4 *Digital Technology: Sharing and Privacy Concerns*

Some mobile applications were used by the mothers to communicate development and therapy details with family members through texts, pictures, or videos captured using their smartphones. The majority of mothers confirmed their use of group conversations on WhatsApp (n = 6), or private accounts on Facebook or Path (n = 4) with family and close friends. Additionally, captured and shared media (videos and photos) were reviewed during visits, either using a smartphone's image gallery or other applications such as Instagram, WhatsApp, Facebook, Path, Nursery Portal, and/or mobile messaging applications (shown in Figure 8). Several reasons were mentioned for sharing; including sharing of joyful moments, achievements or concerns, assessment updates, confirming speech intelligibility, or training other family members. For example, C04 said: *"[The child] said: 'Owl.' I could not believe it. Then I spent the whole time getting her to say it again and I videoed it. I sent the video to everyone and say: 'Can you guess what she is saying?' And they guessed it right and I was like, 'Yes!'"*

All mothers agreed that these sharing channels helped them avoid repeating updates to everyone, especially for tough news, as C02 explained: *"A good thing for just saying it once and everybody sees it and you do not have to then go over and over and explaining yourself."* However, most of the mothers stressed that sharing was limited to their family and very close friends due to their concerns about privacy on social media applications (n = 5) or the children's preferences around online presence when grown up (n = 2). For this reason, they found WhatsApp was more trusted for personal information sharing, as C01 said: *"It is easier on WhatsApp to do it somehow. You do not have to fiddle about with who is going to be on it."*

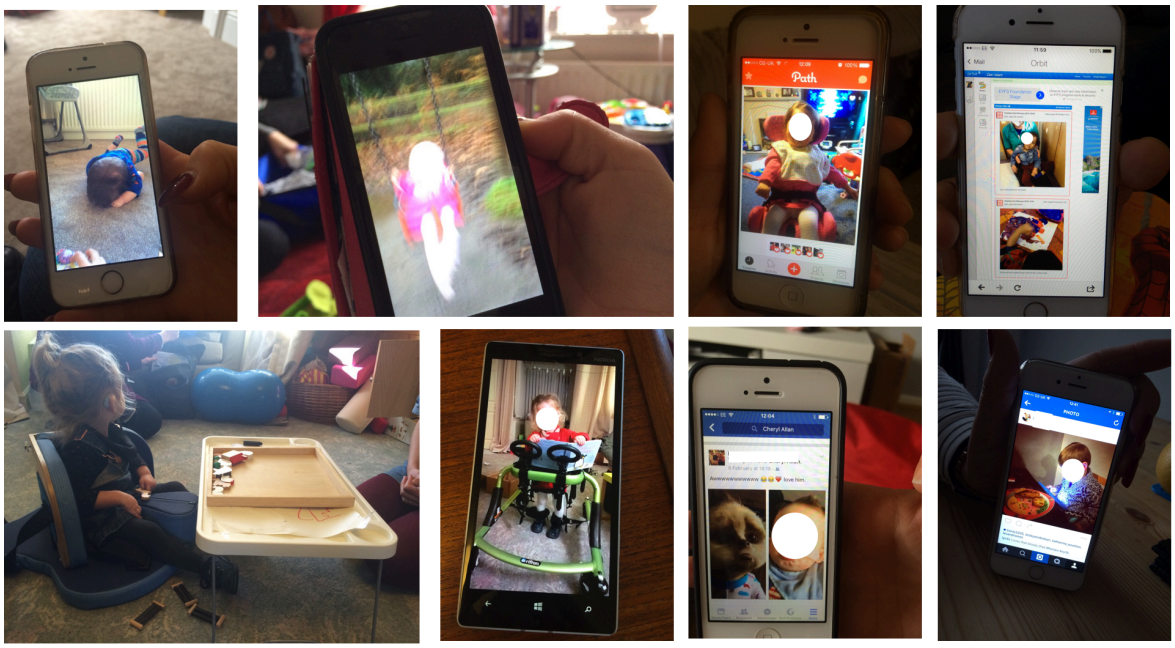


Figure 8. Media captured and shared by the mothers, showing eating, playing, exercise, and communication activities, inside or outside their homes

In contrast, the communication channels used to share with professionals between their visits were limited to phone calls, email/mail when acceptable, or communication through other professionals. For example, T01 explained that *"If they had a question or an issue they might phone us directly, or they might speak to their portage worker and the portage worker would phone us."* Therefore, the therapist's in-between-visits support was limited to simple queries or arranging visit appointments. Moreover, therapists confirmed that they are very restricted as to the media and applications they can use due to strict NHS Information Governance policies relevant to patient information confidentiality. However, two of the therapists confirmed the importance of having an open communication line with mothers for ongoing support, especially at sensitive stages where timely responses are important. As T04 commented, *"Sometimes you go on a visit and you think, I wish you would phoned me about this. Especially on the feeding side."*

3.5 Discussion

In this chapter, we presented the contextual exploration results for parenting children with CP and implementing early therapy practices, along with the existing support channels and techniques. The large majority of primary caregivers of children with CP are women (Brehaut et al. 2004) and in this case study the mothers played multiple roles at the same time,

including caregiving, adopting therapy, and teaching other relevant carers. The findings highlighted a number of challenges facing the mothers to manage their caregiving and therapy adaptation responsibilities. The mothers were sometimes overwhelmed by the children's special needs, as well as the associated demands to learn from therapists, integrate practices into daily routines, teach other carers, and ensure the communication of information between the professional team.

Generally, the findings for parenting children with CP are consistent with the development delays literature (Tang et al. 2012; Kientz, Hayes, et al. 2007; Kientz & Abowd 2009; Liu et al. 2011), which is surrounded by a notion of stress due to emotional suffering, denial, high expectations, hope, and coping. However, we found a greater demand for communication and social support to bridge the gap between the infrequent therapy visits; facilitate learning and caregiving responsibilities beyond the clinical boundaries; coordinate between the multidisciplinary professional team and other caregivers; and support the multiple development needs associated with the children's condition, such as feeding, speech, and movement issues.

Moreover, previous studies of home therapy programmes (Hinojosa 1990; Hinojosa & Anderson 1991) have demonstrated improvements in therapy outcomes when mothers can integrate therapy programmes into their daily routines (e.g. play time). These studies also found that mothers were unaware of their embedded practices, and had concerns about lack of time and the effectiveness of home therapy, which impacted on their engagement in home programmes. By contrast, our contextual study points to higher levels of awareness among mothers and stronger engagement with the parent-delivered programmes. The mothers strived to improve the therapy outcomes and, with therapist support, innovatively incorporated the multiple learned strategies from different therapists into their daily play routines. However, the long intervals between the therapists' visits and prioritisation of healthcare practices according to the child's condition were significant challenges to their commitment to home therapy.

Furthermore, the contextual exploration revealed that video recording and sharing practices through informal channels were already apparent. Through these, parents communicated therapy practices and development progress with professionals or family caregivers. However, the use of informal channels posed a number of issues, including families' concerns

around privacy and data protection policies, as implied by the therapists; and the complexity of data sharing with multiple carers through numerous and disparate communication channels (e.g. WhatsApp, Nursery Portal, email).

With the multiple roles that the mothers play, social support needs, and the established level of awareness and engagement, a centralised parent-led digital solution has the potential to empower the mothers and provide the needed support within the caregiving network. The digital solution can help the mothers to control their role through information sharing, communication, and collaboration with the professionals and other responsible carers. Subsequently, empowered mothers can self-recognise the importance of their role and expertise, and surpass the challenges of raising a child with special needs, as shown in different caregiving contexts (Schorch et al. 2016). A multiple cooperative communication channel, led by mothers, can facilitate both the provision of professional support and collaboration with other caregivers in the integration of therapeutic techniques into daily interaction routines with the children.

Previous work has highlighted successful experiences of integrating bespoke telehealth technologies to deliver remote therapy to children of school age (Keck & Doarn 2014); plus the use of video-based interaction guidance (Kennedy et al. 2011; Balldin et al. 2018) to coach the parents of preschool children during clinical visits (Baxendale & Hesketh 2009; Pennington et al. 2009; Pickles et al. 2016; Green et al. 2010) or to facilitate data capture and behaviour assessment (Hayes et al. 2008; Hayes et al. 2005; Mamykina et al. 2008). Additionally, video-based technologies have been introduced in various ways to support different therapy practices. Video modelling was introduced by Custodio et al. (Ulgado et al. 2013; Custodio 2016) to allow the learning of skills by watching a peer video for imitation. Video capture has also been adopted in different contexts and for different special needs as part of the video feedback intervention (Balldin et al. 2018; Kennedy et al. 2011; Green et al. 2010). In this case, the video recording provides concrete material for reflection. Other video-based solutions were designed for direct intervention and behavioural assessments, but were not controlled by the parents, nor did they capture the whole context of the interaction (Hayes et al. 2008; Hodges et al. 2011; Marcu et al. 2012; Nguyen et al. 2009).

In opposition to these works, our contextual study explores the need for social support and the opportunities for digital technologies in this space, rather than delivering a specific training

approach or behaviour assessment. Without adequate support, the mothers struggled to develop a holistic view of the child's development, and to integrate and share the multiple therapy programmes, while maintaining commitment and confidence and being able to identify progress. Thus, there is a demand for a suitable digital solution that fits the current information age and blends into the parent-child daily activities, to be controlled and led by the mothers, along with capturing the necessary level of details for support. With the identified desire to share visual media to convey mothers' concerns, the video-based records can facilitate discussions between the therapists and mothers based on individualised context-based interaction. Such videos of mother-child interaction would leverage the therapists' understanding of the real context and interaction patterns. This cannot be achieved during a home visit because of time constraints or the state of a child's health (Nazneen, Rozga, et al. 2012). Given the prior success of video coaching solutions, and our mothers' existing video-sharing practices, we perceived conclusively that video capture and sharing technologies have the potential to deliver the needed support to mothers of children with CP and their therapists. However, further investigations are needed to explore the coaching techniques and the potentials of remote support, in order to assess the practicality of video-based solutions to deliver remote support in the indirect-therapy context.

3.6 Summary

This chapter has described the eSALT case study and the results of the first design phase exploring the reality of indirect therapy programmes from the mothers' and therapists' perspectives. Through the contextual exploration, revealed the challenges facing the parents of children with CP and indirect therapy programmes (related to RQ1). The contextual phase highlighted the potential of video capture and sharing solutions to support parent-delivered therapy and alleviate the challenges facing mothers with therapy practices. Therefore, in the next design phase of this case study, we engaged in a user-centred exploration of the feasibility of parent-led digital video-based solutions to support home therapy programmes. In the next chapter, we will introduce the next design phase – which engages the mothers and the therapists in the design process – and discusses the resulting design of a video-coaching technology.

Chapter 4. eSALT: Video Coaching Design

4.1 Introduction

The previous chapter consolidated the contextual needs for home therapy programmes and parents of children with CP. The initial contextual exploration phase revealed the dramatic changes in the lives of families and the overwhelming responsibilities felt by mothers, as the main caregivers, in having to adapt home therapy programmes and coordinate with multidisciplinary teams of professional therapists. The demands of care and care management, coupled with the limited time they had available and the infrequent therapy visits, made these mothers hard to engage in therapy practices. Furthermore, though communication practices existed across the social networks of the mothers, they did so in a complex and overwhelming manner in which multiple online or offline techniques were employed.

These communications practices demonstrated the various dimensions of the mothers' needs, including information and emotional and physical support. Consequently, these needs extended beyond development data tracking (Kientz & Abowd 2009; Kientz et al. 2009; Kientz, Arriaga, et al. 2007), assessing the child's behaviour (Marcu & Hayes 2010), or facilitating therapy protocol implementation for the professionals (Kientz, Hayes, et al. 2007; Pykhtina et al. 2012a). Videos and photos have previously been identified as useful tools for people to reflect on their practices (Kennedy et al. 2011), and the mothers showed their preference for video capture and sharing when communicating with their caregivers' network. The importance of designing for social support, and recognising the expertise of non-professional caregivers, has been identified in related areas of caregiving (Schorch et al. 2016; Hayes et al. 2014). Thus, we realised the importance of designing a remote communication platform that would scaffold the existing relational model through collaboration and partnership with therapists, as well as with other carers for their children. Further design investigation was needed to co-design and discover the potentials of remote coaching for indirect therapy.

In this chapter, we will introduce the second phase for co-design and feasibility exploration of coaching technologies to enhance professional support. Initially, we examined the mothers'

abilities to capture and share video recordings of their play session at home in a pilot study, which was then followed by a series of workshops that focused on exploring the coaching techniques of the indirect intervention and consolidating the design requirements. We concluded with introducing a number of design goals that led to the design and development of KeepCam, a video coaching technology, which aims to improve communication and collaboration between professional therapists, mothers, and members of their wider social networks.

4.2 Phase 2: Study Design

The second phase was aimed at understanding the potential of new or existing technologies and designing technology to support and respond to the identified challenges. Building on the outcomes of the contextual exploration phase, the requirements for support of parent-delivered therapy, and the existing social media behaviours of the mothers, we explored the feasibility of video coaching technologies through a WhatsApp pilot study, followed by design workshops with the mothers and therapists separately.

In the contextual phase, we had noted that WhatsApp was used by many of the mothers for sharing updates about the child's development with their families. The material shared with the other carers included text messages, photographs, and videos; but there were some privacy concerns, as discussed. A clear requirement was identified for the design (or reconfiguration) of digital tools to facilitate the integration of various communication channels, in a manner that could flexibly support different sharing scenarios, as well as simplifying the data capture and sharing processes. Therefore, in this design phase we focused on exploring the existing communication behaviour further with the mothers and therapists, and discussed the feasibility of introducing video coaching solutions as a possible support mechanism.

WhatsApp Pilot Study

Building on the existing video-sharing practices of the mothers, this design phase started with re-appropriation of the current technology using WhatsApp to mimic the experience of video capturing and sharing between the mothers and the therapists. The WhatsApp study was used as a tool to observe first-hand the mothers' natural behaviours and any barriers with the available technology for data capture and sharing, without imposing new technologies or protocols on their practices. We conducted the WhatsApp pilot as a preliminary stage for the

second co-design workshop; all of the seven mothers participated. The pilot lasted for one month and aimed to sensitise mothers to the experience of mobile video coaching. Each mother was provided with a tripod and a Bluetooth selfie-button to remotely control the default smartphone camera app (shown in Figure 9).

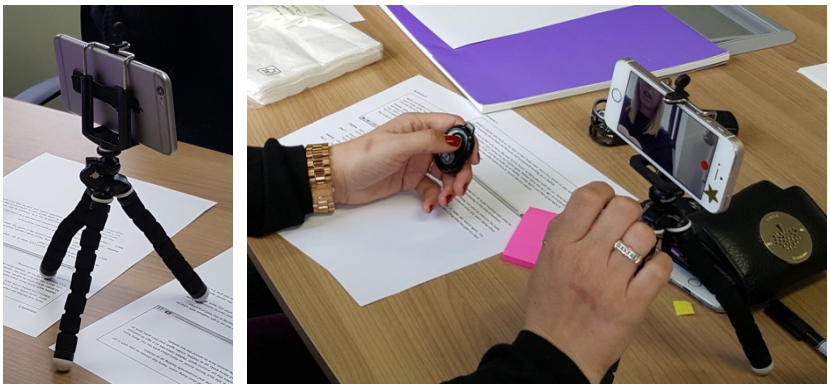


Figure 9. Gorilla tripod used to grip a smartphone and stabilise on any surface (left); Bluetooth button held by the participant to control the camera remotely (right)

The mothers were asked to use their personal smartphones and capture any play session showing the parent-child interaction, as they usually capture it when sharing with other carers. The only specific recording instructions provided were to create video recordings that were less than two minutes in length and that showed both interaction partners and any objects used. The mothers were advised that they might receive feedback regarding the recording setting and quality to confirm recording suitability for therapist review, but that no therapy coaching would be provided at this stage.

We received the videos and relevant messages via a dedicated research smartphone and mobile number. The main aim of this pilot study was to examine the collected videos to assess the ability for using the parents' smartphones to capture and share videos for therapy reflection. We were also interested in uncovering any social and sharing concerns of the parents, such as issues surrounding self-perception and privacy. At the end of the pilot study, the video recordings were analysed; the outcomes were used to structure and scaffold the capture and sharing discussions in the design workshops.

Co-Design Workshops

The workshops were arranged following the sensitising exercise using WhatsApp. We conducted two workshops with the mothers (planned for three and four mothers in each) and one workshop with the four therapists. All mothers agreed to attend the workshop in advance; however, three of the mothers were unable to attend due to unanticipated caregiving responsibilities on the day of the workshop. Alternative arrangements for another workshop were not possible due to the children's health condition at that time. Therefore, two workshops were held with just two mothers in each, and one further workshop was held with the four therapists. Each workshop lasted two hours, and was audio recorded, transcribed, and anonymised. The workshops were designed to help us to establish a better understanding of current therapy coaching experiences, and to explore parents' and therapists' views on, and the possibilities for, a remote video coaching solution.

The co-design workshop was structured to reflect on the WhatsApp video capture and sharing experience, and to explore the perception of coaching in indirect therapy and the possibilities for remote support through video-based technology. The workshop consisted of three main activities: 1) a semi-structured and open-ended discussion around video-sharing experience and reflecting on WhatsApp practice (mothers only), 2) use of predefined personas and scenarios to discuss the current coaching techniques and the possibilities for remote coaching, and 3) brainstorming and reflection on video coaching paper prototypes for technology design. The workshops started with discussions around the experience of video capture and sharing: the mothers were asked about the equipment used, their use of different smartphone cameras (i.e. front/back), their integration of data capture into their daily routine, their experience of video editing, and any challenges faced.

The second workshop activities initiated discussion of a possible video coaching application intended to be led by parents to remotely support the therapy and communication with the other caregivers. Using their smartphones, parents would be able to share a video recording of parent-child interaction, annotated with their comments, and get feedback from their therapist. Therapists would be able to annotate the recording with comments and engage in coaching discussions via their smartphones. Similarly, this communication channel could be used with other carers (i.e. family, nursery staff) or their professional therapists' team. Personas and coaching scenarios were used to engage the participants in reflective discussion and were developed based on (anonymised) families' collective experiences as identified in the

contextual exploration phase. (See Appendix B for the design persona and scenarios). The focus was on further exploring the participants' perceptions of the current coaching practices and the potential of remote asynchronous video coaching to provide support.

The workshops concluded with a co-design activity using paper prototypes to establish a more focused discussion and identify the design elements of a video coaching technology that responded to the participants' needs. The support equipment (i.e. the tripod and wireless button) was shown again, along with the prototype to facilitate the discussions (as shown in Figure 10). The prototype was sketched using the Balsamiq wireframing tool and replicated the sharing scenarios discussed in the second workshop activity.

An interactive version of the prototype was made available for participant review on smartphones using the POP mobile app. A sketched prototype was chosen to focus the conversations and feedback on the design functionality rather than on the actual interface representation, and to avoid the discussion barriers brought by high-fidelity prototypes. The prototype interfaces were designed similarly for therapists and mothers; only the conversation contents were different, as shown in Figure 11 and Figure 12. *eSALT prototype for mothers*. A printed version of the sketched interface was also made available during the workshop for discussion and note-taking.

Figure 10. Video coaching prototypes used in the co-design workshops

Figure 11. eSALT prototype for therapists

Figure 12. eSALT prototype for mothers

4.3 Phase 2: Feasibility Findings

As a result of the design engagement activities, we found that mothers and therapists had a shared understanding of the coaching concepts and the challenges surrounding integrating them into their daily routines. Moreover, we identified clear benefits and challenges of integrating the video coaching intervention into the current healthcare model. In this section, we report the participants' understanding of coaching elements in the indirect SLT and the practicality of data capture and sharing, along with the feasibility and challenges of the remote video coaching solution.

4.3.1 *Perspectives on Coaching in the Indirect SLT*

In the indirect therapy programmes, the mothers and therapists reported that mothers were seeking confirmation of strategy understanding, guidance, feedback, encouragement, reassurance of the practice's correctness, and extending advice about the next goals. As a response to these needs, all agreed that the professionals should try to promote mothers' confidence through discussions rather than predefined therapy instructions. Therapists and mothers had similar views on the coaching approaches adapted in the indirect therapy to meet these needs. Coaching was described as two-way personalised and responsive communication that moved from strategy awareness to implementation in their daily activities, as T01 explained:

"Kind of behaviour change. It is not just about giving information so that they have more knowledge; it is about actually moving them from an awareness of these strategies, to actually implementing them in daily activities. So, the coaching is about kind of, you give the information, but then the coaching is more about actually looking at what they are doing, and bringing out more of the positive stuff, and tweaking, and kind of helping them to adapt some of the things that would not be as useful."

The therapist's role is extended beyond introducing therapy strategies to the need to understand the existing interaction pattern in the parent-child natural environment and adapt these strategies accordingly. Consequently, the mothers felt the strategies introduced were naturalistic, as C07 said: *"Something you already know, but to coach you as to how you maybe could improve it and do it better."* Thus, with the gradual introduction of strategies based on the needs, the coaching techniques were found to be helpful to manage parents' expectations, and to understand the stages needed to achieve their goals.

Additionally, therapists noted that coaching is also about reinforcement and reiteration of advice for encouragement and confirmation of the practice's effectiveness. Mothers found guidance was provided in a way that was not intimidating, was easy to cope with, was encouraging, and built their confidence in order to point them towards the skills they already had. Learning from watching was discussed by the mothers as a better way of learning, as C02 commented: *"Rather than being told something, it is easier to see and learn from somebody doing it. It has made it easier for me by seeing them doing it to them telling me how to do it. Watching is definitely a better way of learning."* As a result of the home therapy

programme, the mothers found coaching helped them to explore different ways to approach problems by themselves; thus, allowing them to own the ideas, realise their own expertise, recognise the importance of their role, and have the freedom to apply the ideas in their daily interactions with the children.

4.3.2 *Practicality of Capturing and Sharing Videos*

Mothers confirmed that smartphones were part of their daily lives, and they were already engaging with some of the video capture practices, as C07 said: *"I am constantly taking photos of him and videos... It is just what I am already doing."* To facilitate the video capture task during the WhatsApp pilot study, the mothers had been provided with tripods and selfie-buttons. The mothers also found these helpful in order to freely play and focus on interacting with their child. Two of the mothers found the tripod helpful to cover up the smartphone, keeping it out of the child's sight; or else they used the back camera to avoid distracting the child. However, the mothers reported the challenge of getting the right camera angle to capture both the mother and the child, especially at the first attempt and when the back camera of the smartphone was used. Thus, the use of the front camera was reported to be more practical to set up and review the recording.

Furthermore, the mothers found it easy to share videos through WhatsApp, but they reported a need to trim the duration of the videos before sharing to focus the content of the video or delete distractions such as the appearance of other children in the family. During the trial, the mothers shared several recordings, ranging from one to four videos per mother (shown in Table 2). These videos typically centred on the child, either alone or interacting with the father, mother, siblings and/or other relatives. Meanwhile, the therapists emphasised the importance of context and parent-child presence in the video recording for assessment, as T03 explained:

"If you are looking to support communication and interaction, then you need to look at both partners. So, we would want to be thinking about, how is the parent responding to this? It might be great that we have seen a child say a word on a video clip, but if you do not know the context you do not actually know how useful that was. Was the child copying the word? Or did they see something? Have they commented on it? Have they requested that thing? And all those things are very different."

ID	Number of videos shared	Duration of each video (minutes:seconds)
C01	3	00:14, 01:37, 03:00
C02	4	00:38, 01:33, 00:38, 01:12
C03	1	3:51
C04	3	00:15, 00:15, 00:15
C05	3	01:33, 01:16, 03:00
C06	2	01:26, 00:43
C07	2	01:54, 02:01

Table 2. Videos shared during the WhatsApp trial

Mothers created these recordings during mealtime, exercise, or playtime using paints, bubbles, or the BigMack communicator. The recordings were made in several locations in the family homes, including the kitchen, the living room, and the nursery. The mothers reported being less anxious about the location of the activity, as they were more focused on getting a good-quality recording. The mothers also reported that their children were not distracted during recording, since they mostly did not notice the camera; except for one daughter who, when she noticed the camera, initially shied away but then posed. The mothers said that they were more focused on the child and forgot about themselves, regardless of their anxiety at the beginning; except for one who described herself as being very distracted by the camera. As C05 said, *"I think it is just like anything. You just eventually get used to doing it, where I have done a few for that through the WhatsApp or for myself."* This was confirmed by our observations of the shared videos; the mothers were mainly focused on their interactions and play sessions and occasionally checking the camera status; except for one mother who was self-conscious. Samples from the recording opportunities and settings are shown in Figure 13.

Various recording opportunities were based on the mother-child time for playful practices. These varied between families according to the mothers' responsibilities and working hours and the child's readiness to interact. While the mothers were able to fit video coaching into their daily routines, they expressed their need for reminders and prompts. Therapists suggested that having the video coaching solution as part of a therapy approach would simplify integration into their work routines and reduce the expectation for immediate responses by setting a weekly slot for video reviews to be communicated to the parents.

Therapists also expressed their preference for asynchronous interaction, since it is logistically hard to manage the review time with the parents' availability.

Figure 13. Snapshots from the videos captured by the mothers

4.3.3 *Perceptions of Parent-Led Video Coaching*

Therapists and mothers reported that video coaching would be beneficial for providing ongoing support and feedback between and during the visits. The mothers explained that the support channel would help them to access guidance and catch up on questions they forgot to ask during the visit, as C05 said: *"You are not waiting for the next visit at your door or the next time you see your therapist, which then you may have forgotten these things you want to discuss."* Therapists revealed that they were easy to contact between home visits and this is considered part of their job. Additionally, therapists confirmed that video coaching would be useful to provide a channel for monitoring the mother-child activities and scheduling additional visits when needed.

"Sometimes, it might be quite complicated, and you cannot just put that in a message ... You might be in a situation of saying – 'Thank you for this, I will come and see you and we will look through it.' Perhaps use it more for the videos, to facilitate your visits and also to know when to time the visits because you could see how they are doing." [T04]

Moreover, further support through group conversations with the multidisciplinary team was discussed to be helpful for maintaining a holistic view of the child's development (for the mothers) and facilitating the integration of therapy plans (for the therapists). For example,

C04 discussed how *"Even the same video, I can be showing it to other therapists because I really like the idea of a holistic view. So often I will take a video and show lots of people because it is all about her socialising and her doing something physically and her overall progress ... The thing that takes a bit of time is just setting up the camera, but that is not long. I think because it is using a mobile phone, it is with you all the time anyway."*

The therapists and mothers believed that video coaching is useful for recording advice, potentially resulting in better understanding and application of the practices and strategies. The mothers added that written therapy techniques through conversations would help them to remember the advice and easily share it with the other carers. C01 said: *"Sometimes you have an appointment and you are trying to absorb everything that is been said but at the same time [the child is] busy doing something, [his brother is] there crying, and you are trying to take it all down. Sometimes it is fab just to get that hour after they go to bed at night to read through your messages. It would be good to go back and have a look at that type of thing."*

The video review practice was expressed by the mothers to be useful for discovering missed interactions and achievements, as C02 said: *"We noticed [the child] saying a word on that video that I did not even pick up on him saying. He said 'Gruffalo'. He was watching it on the telly and he said it, but we did not notice until we watched the video back again."* Also, all agreed that reviewing videos was helpful for referring to previous progress for encouragement when the child's progress had plateaued, as well as for self-reflection. C01 explained:

"I find myself going back through videos because obviously I feel like he is plateaued. He has not done anything different for a while. Then I will go back and have a look at one and think – Oh my God, he was just pulling himself about with his arms. He was not using his legs at all then. He was not even making any kind of noise. So, it is good to have something like that to go back on and look at the difference."

Additionally, therapists and mothers emphasised the benefit of having a video focused on specific interaction to establish a visual and concrete discussion rather than relying on verbal communication alone. T03 expressed how *"It is better, because it is recorded, and it is the focus on the bits that you want to comment on which is good for us."* Likewise, therapists and mothers proposed that videos would provide realistic examples for better understanding of the interaction context and for planning suitable coaching strategies. All promoted the use of

video capture during visits to reflect and reinforce skills as well as to share strategies with other caregivers. For instance, C04 commented: *"My mother-in-law has done it […] I think she has videoed [the child] with her therapist for herself; for her own, sort of, reference, so that she feels more confident with stuff."*

4.3.4 *Anticipated Challenges of the Parent-Led Video Coaching*

Through engaging with our WhatsApp trial and reflecting on their therapy coaching, mothers were able to anticipate a number of potential challenges that would need to be overcome for parent-led video coaching to be a viable solution moving forward. Therapists reinforced the view that video coaching is a way to support home visits but not a replacement. Also, therapists and mothers agreed about the current lack of visual resources to introduce new strategies.

Additionally, all participants agreed that it would take time for the mothers to be comfortable about recording and capturing their videos without distracting the children. Some of the therapists expressed concern about the challenge of "false" interactions due to a child's awareness of the camera or a parent's self-consciousness when filming, as T01 expressed: *"I guess if the child is more distracted by the camera, or using the camera, looking at the camera, particularly if they are seeing themselves on it, then that is not a real interaction that you are seeing anymore."*

Furthermore, therapists suggested that written comments lack non-verbal communication, which is needed to ensure the parents' understanding and explore their feelings. Moreover, text-based conversations can result in miscommunication, which might result from the perceived tone of a message or issues of literacy level. T02 said: *"You cannot quite read a parent's facial expressions, so sometimes you might give them a piece of advice, and then you can tell by their face, that they think you are talking rubbish… so you do not get that bit of feedback from them. And then, there is that fact of all the non-verbal stuff you pick up from a face-to-face conversation, or a conversation on the phone. That you can give a bit of criticism or ask a critical question, rather than when it is written."*

Finally, therapists discussed the organisational challenges of integrating into the NHS systems; these include the cost of equipment, and organisational policies. Therapists explained that the Information Governance policies of the NHS restrict their use of most

digital technologies due to privacy and patient confidentiality concerns. However, these constraints apply to sharing but not to the use of parents' personal devices during the visits. As T04 explained: *"I have been in a session, and the family have videoed me, because they had turned up at the home visit, and they had like, just so we remember, but they wanted a recording of what was going, so that they can then look back on it. So, for that, that was them doing it, that was their recording. It had no information governance, kind of pushing."*

4.4 KeepCam: Mobile Video Coaching Technology

Parent-delivered therapies can create an overwhelming burden on mothers as a result of less frequent home visits and decreased professional support (as we found in Chapter 3). Video coaching technologies were perceived by mothers and therapists as having the potential to offer valuable support to mothers of children with CP for home therapy practices. The designed solution for parent-delivered therapy should empower the parents' expertise, allow self-management without adding complexity or stress, and blend the data capture and coaching techniques into parents' existing routines. In response to the existing challenges and needs, KeepCam was designed as a smartphone retrospective video capture and coaching technology, to create short video segments of specific actions that parents found challenging in their existing home therapy practice, and to share these moments in different ways to access support.

KeepCam incorporates and adapts the design elements from previous systems (Hayes et al. 2008; Hayes et al. 2014; Kientz & Abowd 2009; Kientz et al. 2009; Nazneen, Rozga, et al. 2012) to meet the needs of parent-delivered therapies. In addition to ongoing support between visits, the video element of the coaching system has the potential to provide support within the visits. For instance, the mother can show short videos from mother-child natural setting for in-session reflection or when the child show less engagement. Furthermore, during the visits, therapist will be able to create short segments of videos where each segment is focused on specific actions noticed in the mother-child interaction. These videos then may used for discussion during the visit or for the mother to reproduce learned strategies while practicing at home (rather than relying on paper-based guidelines). Hence, the short videos have the potential to scaffold reflection both between and during home visits. In this section, we discuss and describe the specific design principles of KeepCam, along with the system elements and how it might be adopted in the therapy context.

4.4.1 *Design Rationale*

Current home therapy practices encourage the parents to adopt and adapt the learned skills and therapy techniques in their daily routines with their children. Prior studies have discussed how home visits were based on prescribing therapy programmes and have suggested assisting the mothers in the strategies' implementation rather than teaching them (Hinojosa 1990; Hinojosa & Anderson 1991). However, our study indicates that the therapists adopt the coaching principles to deliver home programmes and embed the therapy practices in the child's daily routine. Coaching principles involve guiding the individuals to increase their competence, commitment, and confidence, and facilitate the achievement of their goals (Allen & Huff 2014; Olsen 2014). Rush et al. described how observation, reflection, and assessment are part of the coaching process (Rush et al. 2003); our study shows that mothers and therapists are adapting these principles and stages in their home programmes. Therefore, these coaching principles can be extended beyond the therapy session and delivered through remote interaction, which can reduce the demand for frequent visits and facilitate the integration of practices into the various parent-child interactions in their real environment.

Changes in how home therapy programmes have been delivered have resulted in effective outcomes on the parents' skills (Schrader-McMillan et al. 2012). However, the irregularity of visits still leads to a perception of a lack of support. Coaching continuity has been recognised as a fundamental factor for achieving coaching goals (Allen & Huff 2014; Olsen 2014; Rush et al. 2003), and our findings indicate that mothers need more support rather than more therapy. Given that the main focus of indirect therapy is to coach and support the parent rather than directly conducting therapy sessions with the child, while technology might have an essential role in resolving the debates and demands for more frequent visits, it must be designed to empower mothers and promote these interactions without risking the values of coaching and home programmes. The findings confirmed the importance of physical visits for introducing new strategies and discussions of critical matters, but also revealed the need for remote support during the long intervals between visits for coaching elements such as reassurance, encouragement, promoting confidence and commitment, reinforcement, and reiteration.

The acceptance of tele-practices in school settings has previously been demonstrated by Hines et al. (Hines et al. 2015), and the initial contextual phase pointed to the potential value of extending this to include preschool programmes. Telehealth technologies have shown the

potential to improve the service-delivery model of parent training programmes (Meadan & Daczewitz 2015; Nieuwboer et al. 2013; Hall & Bierman 2015; Cason 2011; Vismara et al. 2012). These technologies focused on delivering therapy sessions remotely, or on providing online training courses for parents to join which suited their availability. Furthermore, video-based approaches have been proposed for the direct delivery of interventions, to collect and track development data, to facilitate clinical assessment, and to augment face-to-face sessions (Kientz et al. 2009; Marcu & Hayes 2010; Custodio 2016; Kennedy et al. 2011). However, these digital interventions and selective data capture were not portable and did not facilitate integrating therapy practices into the daily routines of the parents and children to promote development.

Therefore, based on the findings of previous applied studies (Hayes et al. 2008; Hayes et al. 2014; Kientz & Abowd 2009; Kientz et al. 2009; Nazneen, Rozga, et al. 2012) and the design engagement activities held in this study, we developed five design principles for a mobile technology to support the needs of parent-delivered therapy. Generally, we leveraged the parents' own smartphones as the source of data capture and integrated informal communication technologies into home therapy practices. In this section we describe the specific design principles of KeepCam. These include self-collected data, embedded and concealed technology, retrospective capture, lightweight communication channel, privacy, and control.

DG1. Self-Collected Data

In our study, mothers expressed the importance of self-reflection and self-discovery through the use of videos of mother-child interaction; they found the experience of self-review particularly useful in identifying their children's skills and progress. Thus, technology must support the collection of videos in a way that allows parents to self-observe and self-correct through examination, reflection, and discussion of these videos. Several systems have highlighted the capabilities of coaching and reflective thinking based on digital record keeping (Mamykina et al. 2008; Kennedy et al. 2011; Kientz & Abowd 2009). Therefore, systems designed in this context should enable the parents to employ self-coaching strategies, which have the added benefit of raising self-esteem. The self-collected videos can therefore serve both as an evidence base for achievements or concerns, and as a way to scaffold discussion when a child's progress is not readily apparent to the parent due to proximity and the slow nature of development. Visual media can support memory, facilitate recall, and

enable parents to notice progress (Mamykina et al. 2008; Kientz & Abowd 2009; Kientz et al. 2009).

Parent-delivered therapy is based on changing parents' behaviour to develop the child's communication skills. In this therapy programme, professional therapists explore the parent-child interaction by observing a play session and assessing the child's skills. Technology can facilitate this assessment and provide the needed support so that the coaching can be delivered remotely. To enable this remote coaching, the interaction data is shared by capturing videos showing the child, interaction partner, and the surrounding context (as it might influence the interaction). This builds on existing video-sharing practices that the parents use to communicate achievements or convey concerns to therapists or their family. In addition, smartphones are often chosen by the parents to capture these videos due to their mobility and availability. The front camera is mostly used as a mirror to adjust the recording angle. Thus, we need to supply the parents with simple, mobile, and automated capture technology. Automated data capture technology has been used to allow continuous recording of specific interactions for post-incident reflection, yet the most used video recording device was a baby monitor or standard camera recorder (Kientz & Abowd 2009; Kientz et al. 2009; Hayes et al. 2008). In this study context, digital solutions should facilitate self-collected recordings by building on the parents' existing practices of videoing using their personal smartphones, while at the same time employing automated mobile data capture techniques.

Progressively, it is anticipated that the parent will establish and maintain video archives that can be used for self-coaching and progress monitoring. This follows Kientz et al.'s findings that record keeping and tracking cause stress for the parents of young children (Kientz et al. 2009); thus coaching technologies should allow tracking of achievements based on video captures, while limiting stress. Thus, video records and associated communications must focus on supporting parents to reflect on their child's progress based on the previous videos and to understand their child's development, without introducing a competitive burden. In this respect, parent-collected video records are particularly appropriate.

DG2. Embedded and Concealed Technology

Mothers expressed their motivation to gain the needed support through remote coaching technologies. However, this interest should not interfere with the challenges of embedding technology into their demanding care routines. Our study confirmed previous accounts

(Hinojosa 1990; Hinojosa & Anderson 1991) of the overwhelming nature of caregiving and therapy management of children with CP. Any addition or augmentation of existing therapies must be wary of introducing additional burdens. In this respect, coaching based on parent-collected video has the advantage that smartphones are already a tool of everyday life for mothers. Furthermore, we can build on existing experiences with technology and support the mothers by using familiar and standardised interfaces for data capture and sharing.

Our study also indicated that children with CP demand high levels of physical support and attention, which makes the creation of video content while maintaining their position and engagement with their child particularly challenging for parents. In play sessions, the parent is immersed in the interaction, along with the physical and attention demands of the child with CP. As the parent needs to capture these moments while interacting with the child, the video recording task should be non-disruptive and blend into their daily routines without adding burdens. Due to the child's condition, the parents usually prepare the area before the play session. Therefore, while preparing the play area, to facilitate the integrating of data capture into the play activity, the mobile recording device can be installed out of the child's sight to avoid distractions (e.g. using a portable *Gorilla tripod* to place the smartphone where it can record the child, parent, and the environmental context in which interaction takes place). It can then be controlled remotely (e.g. using a wireless selfie-button to control the recording). Due to this remote recording setup, attention should be given to integrating non-disruptive recording alerts to minimise demands on mothers (e.g. an on-screen notification and an audible feedback).

DG3. Retrospective Capture

Focused interaction capture can facilitate purposeful discussions and specific behaviour analysis, compared to a full interaction recording (Hayes et al. 2008; Mamykina et al. 2008; Nazneen, Rozga, et al. 2012). Therefore, short video content that only captures the interactions of interest (such as achievements or concerns) can enable more concrete therapist-parent discussions around specific interaction patterns. These videos should also be practical for review by the therapists and provide decent guidance without overwhelming them with long content that is difficult to analyse. The WhatsApp trial provided insights into the challenges of concrete data capture. Previous works (Hayes et al. 2008; Hayes et al. 2014; Kientz & Abowd 2009; Kientz et al. 2009; Nazneen, Rozga, et al. 2012) have demonstrated

the feasibility of designing selective capture and access tools using semi-portable devices to support therapy assessment or record keeping.

Consequently, the video-based coaching solutions can allow on-demand retrospective video recording from a buffered video content using remotely controlled smartphones. To capture the moments of interest and to ensure that parents do not miss important events, the digital solution should allow video buffering and recording of the recent past moments on demand. Based on the duration of the videos collected during the WhatsApp trial, the therapists agreed that one to two minutes is sufficient to capture enough of an interaction. However, the videoing element should be flexible so that the exact segment duration can be pre-configured, with the ability to remotely expand it while recording due to the unpredictable nature of the actions captured. This approach can ensure that video recordings are short and easily triggered without interrupting the play and therapy activities.

DG4. Lightweight Communication Channel

Our study also identified the different communication practices, with multiple professionals and family members using different digital applications. The mothers looked for support from professionals or shared their experiences with their family members to engage them in the therapeutic practices. Mothers also assumed the roles of many different therapists and sought confirmation for their integration of the different roles with the corresponding therapists. Previous digital solutions have focused on remote session delivery or data capture for in-session assessment (Aggarwal et al. 2015; Hayes et al. 2008; Kientz & Abowd 2009; Nazneen, Rozga, et al. 2012). Recognising the limitations and scarcity of technologies to support the needs of parent-delivered therapies, a remote, asynchronous, and lightweight coordination and communication tool should be designed for parents, their professional teams, and other caregivers.

The technology should support mothers' needs to integrate their different communication practices into one tool through either individual or group conversations. As in the existing home visit practices, these conversations should remain informal rather than structured or clinical. Group conversations would allow more discussions with a child's multidisciplinary team, address the challenge of arranging and conducting physical meetings, and provide opportunities for the mothers to engage other relatives and easily share updates. As reported

in the contextual study, existing apps such as WhatsApp were desirable for video sharing, communication, and feedback with the therapist teams and family members. Thus, the design of familiar commercial messaging apps can be re-appropriated to enable parents to share videos and be coached by one or many therapists, yet in a secure way. This simple approach is used to enable the parents to initiate the coaching process and provide them with the ongoing support they need between visits. The remote support can be synchronous or asynchronous, based on the time that the parent and therapist have access to the system.

Additionally, any augmentation to the current indirect therapy practices must avoid adding burdens onto the therapists and the parents' routines. Lack of time for more frequent visits was the main issue behind the limited support received; thus the technology should be designed in respect of this constraint. Thus, these solutions should be designed to automatically communicate the expected therapists' response times to avoid the challenge of immediacy of interaction found in messaging applications. Also, to support mothers of children with CP, the system should include prompts and reminders for video capture and sharing to promote more persistent practices.

DG5. Privacy and Control

Data ownership and protecting privacy are among the main concerns surrounding the media captured in various contexts (Hayes & Truong 2009; Aggarwal et al. 2015; Kientz et al. 2009). Despite the benefits of remote video coaching, these video-sharing technologies bring with them issues of privacy and control of data. The mothers were reluctant to give copies of videos of their child to strangers (except for the professional team and the child's caregivers) and sought to have control over the video sharing and access. In our study, the mothers' concerns about the privacy of the shared personal information pointed to the need for them to have full control over these communication channels.

Accordingly, conversation management mechanisms must allow only the mothers to establish self-control of data sharing and access. The mechanism should allow the parent to control who can see and contribute to each video or conversation, without the recipients having the ability to export this shared data beyond the system. Similarly, the parent should be able to revoke access to a video or conversation at any point. Notably, therapists already delegate these responsibilities to the mothers due to legal and professional constraints on information sharing.

4.4.2 *KeepCam: Capture and Sharing Elements*

KeepCam is an application written for iOS mobile devices, designed to run on the parents' own smartphones. The software partitions the user interaction into two distinct elements: the video capture and the coaching communication. This division is designed in response to the diverse contexts in which each part of the application is used; in this section, we explain how each of these elements works.

KeepCam: Retrospective Video Capture

KeepCam is designed for the self-collected capture of moments that cannot be precisely anticipated (DG1, DG3). Parents may expect that a play session could result in some interactions they would like to record, and so can pre-emptively choose to set up KeepCam to watch the session; for example, using a Gorilla tripod (see Figure 9). The video capturing interface for KeepCam launches directly into the default configuration, which records through the front camera while showing a full-screen preview of the image: this allows the parent to easily position the device to record the desired area and to check the camera's field of view at a glance, even at a distance (DG2). A design decision was made to consistently use a landscape orientation for the recordings as this maximises the horizontal field of view; the interface overlays instructions if the user needs to reorient the phone. To support sessions over an extended period, and to ensure the parent knows the device is still watching, while it is active the application does not allow the phone to automatically sleep or turn off the display.

The precise interactions that should be saved are typically noticed after they have already begun. Retrospective video capture, also known as *pre-roll* recording, is commonly used in applications such as dash cams for video evidence of vehicle incidents. Such applications typically record a long loop of video that will eventually overwrite itself, and generally allow the user to indicate that a section is important and should be preserved. With KeepCam, the temporary loop of video is kept short and the captured video promptly discarded unless explicitly saved. KeepCam achieves a balance in allowing the purposeful, retrospective recording of events and their prior context, while limiting unnecessary recordings (DG3, DG5).

The moments of capture are remotely triggered using a small, wireless button (shown in Figure 9). The button can be any of the available remote camera trigger buttons and is seen by

the phone as a key press on a Bluetooth wireless keyboard. Once the recording is triggered, the phone emits a subtle beep as audible feedback to the parent; then video from the pre-roll duration (typically 30 seconds) is stored and an additional post-duration video is recorded (typically 10 seconds). During the post-recording, a flashing red solid circle is shown on the interface. If the capture button is pressed again during this, and up to an "append" timeout afterwards (typically 5 seconds, during which a dashed circle is shown on the interface), then the current recording is extended by an additional post-duration interval. In this way, a parent can extend a capture to incorporate an ongoing event by pressing the button a second time, or multiple times (DG3).

To maximise the users' control over their own recordings, the captured video is stored in the device's "Camera Roll" within a "KeepCam" album. This provides a predictable location for users to find and manage the media in a familiar way, allowing them to review, edit, share, back up, or delete their videos as they would like. Video sharing can then be achieved through KeepCam or any other applications.

KeepCam: Coaching Communication

The coaching communication interface is designed to be easy to use by anyone familiar with other mainstream messaging applications, while ensuring that the user has the required security, privacy, and control (DG4, DG5). The application requires users to be registered and signed in by a verified email address. When the application is started, the initial screen shows the conversations list that the user is part of, ordered with the most recent messages first, along with a count of any unread messages in that conversation. A new conversation can be started; the user must specify one or more of the trusted contacts to have the conversation with. Within a conversation, text messages and thumbnail previews of video clips are shown in chronological order in a standard alignment of incoming messages on the left, and outgoing messages on the right. Video within the conversation is played in a full-screen interface when a preview thumbnail is tapped. Users can send a new message by simply entering the text in the standard way. Video is shared by choosing the required video from the device's Camera Roll, which allows users to send video they have captured by any means on their phone; videos taken with the pre-roll recorder are located in the KeepCam album. Adding annotation comments to any video shared is one of the constraints implemented to promote coaching and reflection.

Additionally, notifications are used to indicate when new messages arrive; informing the user and allowing them to directly access the latest message, and also updating the application icon with a badge to indicate a count of any unread messages. The messages pass through a secured university server and connection, verified to be the correct server, so that the communication cannot be intercepted (DG5). The server deals with a series of requests from the application to send and receive messages, each of which is checked against the user's credentials and permissions. For instance, when the therapist requests access to the shared information, it will be streamed to the therapist's mobile phone and accessed via KeepCam but cannot be exported to their device's "Camera Roll".

4.4.3 *KeepCam in Context*

KeepCam was developed to be used by parents, for video sharing and communication with their professional therapists' teams, family, and other carers. The goal of KeepCam is to deliver continuous support to the carer and stimulate the child's communication skills, regardless of the frequency of therapist visits. KeepCam revolves around the concept of "videoing" moments of interest to access remote support, as shown in the scenario depicted in Figure 14.

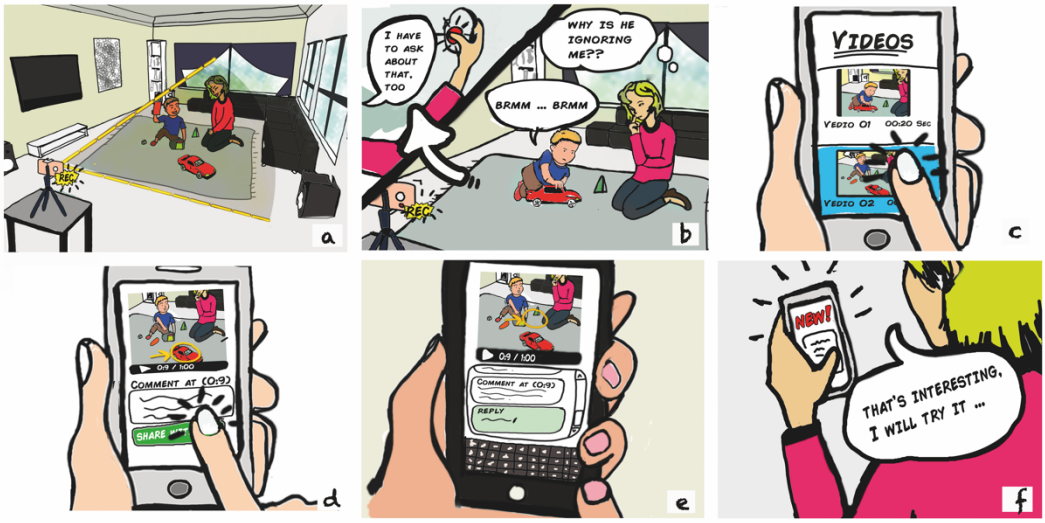


Figure 14. Use case scenario of KeepCam – a mobile app for video sharing and remote coaching.

As part of the play session preparation, the parent will start their KeepCam camera recording and adjust the smartphone field of view using a tripod (DG2, DG3) (Figure 14.a). Then, with the remote button (DG3), the parent will be able to selectively record any spontaneous moment of interaction (such as if the child is babbling for the first time), or other moments of

concerns (Figure 14.b). With each button press, short video segments are archived to the KeepCam album (DG5). The parent can then preview these videos to monitor the child's progress over time, as well as to share interesting moments with other carers (DG5) (Figure 14.c). To establish the coaching dialogue, KeepCam allows the parent to select the video that is most convenient for them to share with others (DG5). For example, the parent might not share a video showing other relatives in the scene.

The selected video must then be attached with comments and shared with the therapist in the way commonly used by existing messaging apps (DG4) (Figure 14.d). The parent can also revoke access to any pre-established conversation or video shared (DG5). These communication and cooperation mechanisms are parent initiated and based on free-form conversations that allow the therapists to support the home practices' implementation in the child's own environment. The therapists will be able to observe the shared video and provide reflective feedback to promote the parent's skills (Figure 14.e). The therapist's feedback is provocative (i.e. asking questions more than teaching techniques), intended to allow the parent to reflect on the interactions and plan their own techniques to achieve the therapy goals. Further details about the therapy coaching techniques will be explained in the therapy programme section. Based on this remote video coaching solution, the therapist will also be able to remotely monitor the parental skills, along with the child's development, and decide about therapy home visits based on needs (DG1, DG5). Meanwhile, the parent can access further support and guidance to better adopt the therapeutic practices (Figure 14.f).

4.5 Summary

This chapter describes the potential and the design of a mobile video coaching technology to support parents of children with CP. The chapter first explored the challenges associated with existing coaching practices and the design feasibility for a remote coaching solution to deliver the needed support. In indirect therapy, the parents are the coachees with the professional and the coachers for their children's other caregivers. We found that there is a real potential for developing less formal communication platforms, led by parents, to help them to manage their roles and access support; but not just for the professional care service delivery.

The eSALT study identifies a number of design implications for future video-based digital solutions led by the caregiver to support mothers of preschool children with special needs;

from augmenting the current healthcare model and enhancing the communication with health professionals, to better social support and sharing with families and peer networks. Then KeepCam was designed and developed as a smartphone video coaching technology to support parents of preschool children with CP and indirect therapy programmes. The system is composed of two distinct elements: retrospective video capture and asynchronous coaching communication. The design process resulted in informing the design of digital solution that balance the needs of mothers and therapists; and focus on the parent role in informing the design of coaching solutions (related to RQ3). However, we still need to review and investigate how the parent-led design features impact the real practices. Therefore, the third design phase focus on exploring the design of parent-led coaching solution through field deployment. The next chapter describes the deployment of KeepCam in a real-life setting with families and therapist and report on how parent-led mobile video coaching tools can be used for continuous engagement with therapy programmes and can facilitate social support.

Chapter 5. eSALT: Therapy Support via KeepCam

5.1 Introduction

As we saw in Chapter 3, there was a significant demand to support the parents' role in the indirect therapy programmes and to facilitate collaboration with their caregivers' network including professional therapists and family. In Chapter 4, we consolidated the design of a remote home therapy support system in response to the needs of therapists and mothers of children with CP. The design and implementation of KeepCam introduce new ways in which technology can support parents in adopting home therapy practices.

In this chapter, we scaffold the design discussion and reflection through a field study of KeepCam as a parent-led mobile video coaching technology, for the mothers of children with CP to access remote support for the indirect speech and language therapy. The developed technology responds to the mothers' needs for support and aims to facilitate remote video coaching, which is initiated by the mothers using familiar technology. With the families and therapist, we explored how the mothers used and integrated the video coaching into their real-life routines to access remote support on their in-home therapy practices. In conclusion, we suggest design considerations and opportunities for digital technologies to support indirect therapy practices.

5.2 User Study

The aim of the deployment study was to investigate the potentials of KeepCam as a remote parent-led video coaching technology and to better understand the therapeutic support needs and behaviours of the parents responsible for indirect therapy delivery. Although the system was designed to facilitate communication with various caregiving groups (e.g. clinical team, family, nursery), the focus of the study was on investigating the parent-therapist communication to understand how the KeepCam selective recording technique can support the indirect therapy programmes.

5.2.1 *The Intervention*

The parent-delivered interventions targeted the parents as they are the primary communication partners and can support the children's development on a daily basis. Indirect therapy focuses on parental behaviour change in order to let the parents have ownership of the skills and the practices needed to support the children's communication as well as embedding therapy practices in their everyday life routine (Pepper & Weitzman 2004; Sussman 1999; Green et al. 2010). Generally, parent coaching techniques are based on encouraging interaction where the child leads and the parent facilitates rather than "teaches" (Sussman 1999; Pickles et al. 2016). Similar, early speech and language therapy techniques are adopted with different populations of children, such as children with speech delay (Pennington et al. 2009) and children with autism (Green et al. 2010). In this deployment study, the therapist (T01) designed the indirect therapy protocol based on the early speech and language therapy techniques. The therapy intervention delivered across six weeks, with a therapist home visit once per week. The therapy programme reported below was based on the therapist description.

The indirect therapy was considered as an ongoing collaboration between the parents and speech therapists to support the children involved and increase their verbal output as much as possible, using the techniques that best suited the individual child. The main focus of the interventions is to coach the parent in a naturalistic manner, without the parent having to act or behave in a way that does not feel right to them. Parents may need encouragement to try new techniques (such as doing unexpected actions to encourage the child to initiate communication), but these are based on the skills that the parents already have.

The interventions follow a similar trajectory with all families, but all stages may not be attempted or progressed, based on the assessment and development of the child. Although the trajectory is fairly linear, earlier stages can be revisited to check skills and assess progress. Moreover, the stages are not prescriptive: if there are approaches used or developed by the parents which are effective in encouraging vocalisation and communication, these will be encouraged. Table 3 lists the main stages of the adopted and designed therapy strategies.

Stage	Speech and Language Therapy Strategy
1	Letting the child lead and getting down to their level to create shared communication experiences.
2	Parents recognise and adapt their communication to their child's timing, using the OWL (observe, wait, listen) approach to ensure that they match their child's interest and communication levels.
3	Parents learn to adapt their level of language to their child's developmental level through appropriate modelling and commenting.
4	Parents use simple phrases within daily routines so that the words become familiar and predictable to the children.
5	Parents learn techniques to encourage their children to initiate communication.
6	Parents learn to expand and elaborate on their child's communication, speech, and play.

Table 3. Summary of projected stages of the parent-delivered therapy protocol – transcribed by the therapist (Baxendale & Hesketh 2009; Green et al. 2010)

These home visits lasted from 45 to 70 minutes, depending on the session plan, distraction level, and engagement of the child. The visit time was pre-planned and fixed for each week, especially for the working parents, but the therapist was very flexible in timing. The visits started with a chat about the child's progress and the previous week's activities. Based on assessment of the child and understanding of their communication patterns, the therapist fitted the evidence-based strategies into the parent-child personal practices. The visit activities were flexible and based on triadic play, as the therapist stated: *"Asking them to have a little bit of free play, the mum and the kid are playing, and then I am sort of sitting observing. And then I will maybe just make a little comment like – 'Oh, did you see him, waited for that there? Maybe next time, if you just wait a bit longer.'"* [T01]

To introduce a new strategy and play ideas, the therapist interacted and modelled with the child to demonstrate to the mother. These visits also involved some discussions to identify suitable places for interaction at home, explain different communication patterns like eye contact, describe the overall communication development process, and show suitable video recording configurations. At the end of the visit, the therapist and the mother planned together for the next week's activities and goals. The mother was provided with a weekly sheet of practices, called *My Communication Toolbox*, to explain the strategy and personalise it with examples to fit the activities into the mother-child communication routines. (see Appendix C for samples of the practices sheets). The therapist explained that this sheet is *"An outcome measure, because you can look and see week to week, and it is something a bit more solid for them to hold onto. Because, when I am not there, if they forget, they can just have a wee look at the sheet. And also, it is something for them to have, to pass on [to other carers]."* [T01]

5.2.2 *Participants*

The field deployment study continued with the seven families (families' details described in Chapter 3), and one more family was recruited for this deployment phase (i.e. eight families in total); family (C08) details shown in Table 4. The mother was working part-time, held a postgraduate degree, and was living with her partner, who was working full-time and held an undergraduate degree. All the families were using the English language to communicate to their child (the therapists providing the intervention were English-speaking) and had experience with social media apps such as Facebook, WhatsApp, and Instagram. We were open to working with any of the caregivers (i.e. mothers, fathers, or other relatives) who were engaged with the indirect therapy practices and visits; however, all the main caregivers during the deployment phase were mothers. Our participant makeup was in line with previous studies, which have shown that the large majority of primary caregivers of children with CP are women (Brehaut et al. 2004).

ID	Mother Age	Mother Employment	Partner Employment	Child with CP (Ages in months)			Siblings (Ages)
				Gender	Age	Age at Diagnosis	
C08	33	PT job	FT job	M	31	8	None

Table 4. Profile of the eighth family – ages are in years

Three of the mothers had to withdraw from the study in either the third or fourth weeks of the deployment due to family circumstances, moving to a new house, or the child had a surgery (a high dropout rate is a characteristic of this group (McGoron & Ondersma 2015; Hinojosa 1990)). One of the mothers (C08) received four weeks of therapy instead of six, due to the family's availability during the deployment phase. Accordingly, the field study conducted with five families and we believe that this is a reasonable setting for the purpose of this field study since we were focused on observing the design features in real therapy context to further understand the participants' behaviours and needs; but not the clinical impact of the remote support solutions. The therapy intervention was delivered by one therapist (T01) to all of the five families. The therapist was one of the collaborating SLT researchers from the Institute of Health and Society at Newcastle University, with six years of experience in the SLT domain.

5.2.3 *Deployment Setup*

KeepCam was intended to be used during the time between weekly speech therapy home visits, with the goal of delivering remote support on therapy practices at home. As discussed on Chapter 4, KeepCam was designed to facilitate therapy adaptation and support parents in using the learned skills in more naturalistic everyday interactions. Through the ongoing remote support, the therapist sought to: encourage reflective learning in the parents, allow them to build on the skills explored in the weekly home visit, provide them with the ability to communicate feedback on progress and share any concerns faced in a timely manner. The field deployment was conducted for six weeks. The mothers were provided with Gorilla tripods (i.e. adjustable tripod that can stand or attached to any surface) and Bluetooth selfie-buttons (see Figure 15), along with KeepCam application and iPhone if needed.

Figure 15. Gorilla tripod and Bluetooth selfie-button (Kamisafe 2018)

We visited the participants at their homes at the beginning of the deployment study, accompanied by the therapist. During this visit, the KeepCam application was installed on the mothers' personal smartphones and they were provided with the tripods and Bluetooth button. One mother was provided with an iPhone for the period of the study, since her Windows phone was not supported by the KeepCam software. For data protection, the therapist also received an iPhone dedicated for use with this deployment study.

Once the KeepCam software was installed, we demonstrated to the mothers how the video recording operated, how to capture specific moments using the Bluetooth button, and where and how they could mount their smartphone using the tripod. A default video length of 40 seconds was chosen, as informed by the therapist's suggestion. KeepCam was configured to capture 40 seconds of video segment once the recording is triggered by the Bluetooth button (i.e. 30 seconds retrospectively, 10 seconds after the trigger), and if the button pressed again

while recoding (i.e. flashing red solid circle will be shown on the interface) then the recording will be extended by an additional post-duration interval (details in Chapter 4). In this way, the mothers can extend a capture to incorporate an ongoing event by pressing the button a second or multiple times.

The mothers were also trained to set up the phone camera so that the parent, child, and joint activity were all within the frame. Moreover, the mothers were advised that they could use this technology to share videos with the therapist (T01) between the visits whenever challenges were faced, further information was needed, or over any other related child development and therapy practices matters. KeepCam allows the mothers to communicate with the therapist in one-to-one private conversation, and the therapist can respond to each conversation received from the mothers separately. Finally, in this initial visit, the mothers' skills and the children's development were individually assessed by the therapist to personalise their therapy plan and track their development for clinical assessment (the clinical study is beyond the scope of this research).

5.2.4 *Data Collection*

Data was collected throughout the therapy intervention period (i.e., over 6 weeks), and included weekly feedback report, individual therapist and mothers' interviews, and a web-based log file of all conversations and videos shared using KeepCam. During the weekly visits, the therapist built on the therapy practices and collected feedback about the use of KeepCam during the week. The therapist was reporting feedback about number of videos captured and shared, and any experiences or issues faced with the capture and sharing functionality. This feedback was collected weekly and included feedback from the mothers and the therapist.

Moreover, all the data were exported from the KeepCam system as "web-based log file", which replicates the therapists' interface of KeepCam and includes all the conversations' held with mothers along with the conversations' messages and videos. The log file was reviewed, with the permission of the participants, to analyse the data shared during the deployment using KeepCam. This helped us to better understand how the mothers and the therapist used the technology during the field trial period. Some of the videos were eliminated from the analysis by the therapist, since according to NHS policies they were considered inappropriate to access.

Furthermore, all the mothers and the therapist were interviewed individually to explore their perspectives and experiences with the data capture and access of remote support through KeepCam. Interviews were held with the mothers in their homes; the therapist was interviewed in their university office. The interviews were conducted two months after the deployment period to allow inclusion of any post-therapy experience, and according to the families' availability. Furthermore, web-based log file of KeepCam was reviewed prior to the visits to drive the interview discussion and investigate further details about the data capture and sharing experiences. The semi-structured interviews each lasted for one hour and covered a variety of topics, including 1) the role KeepCam played in supporting the home therapy programme, 2) how the technology and the therapy protocol were integrated into daily life, 3) the associated professional and social support, 4) any concerns about privacy and data protection, and 5) any challenges faced during the remote therapy delivery. See Appendix C for the interview guides.

During the interviews, and whenever applicable, the mothers were asked to open the relevant recordings or messages shared and reflect on their experiences. Additionally, through KeepCam system we can only access the videos shared by the mothers. Therefore, during the interviews, the mothers were asked about the number of videos captured using KeepCam, since these videos were stored in their device's "Camera Roll" within a "KeepCam" album. However, these numbers reflect the video capture practice, but not all home therapy exercises. For instance, the parents' might have practiced the therapy but did not capture any video if nothing interesting happened, if they forgot to record, or if their smartphone were not available. Finally, each interview was audio recorded, transcribed, and anonymised. The data collected from the different methods (interviews, log file, feedback report) from all mothers and the therapist were compared, combined, and analysed using qualitative thematic analysis, as described in Chapter 3.

5.3 KeepCam Findings

During the six weeks of the KeepCam deployment period, the mothers showed a high level of engagement with the indirect therapy programme and remote support. The mothers created a total of 420 videos and shared up to 148 of them. Most of the shared videos (n = 97, 66%) were created using the standard duration without extending (i.e. 40 seconds), while the rest were extended with the longest video being 120 seconds (mean = 41.41, SD = 14.68). During

some weeks, which overlapped with family or school holidays, some of the mothers (n = 3) had arranged with the therapist not to share videos. Continuous dialogues between the mothers and therapist were held weekly to extend the discussion on home practices based on the videos shared. Table 5 shows the total number of videos, along with a breakdown of the number of videos and messages shared per week for each of the mothers and the therapist. In this section, we detail the ways in which the design of the parent-led video coaching technology supported the indirect therapy and adoption of the strategies in the daily routines of the parent-child interaction.

	WEEK 1			WEEK 2			WEEK 3			WEEK 4			WEEK 5			WEEK 6			POST			TOTAL VIDEOS	
	V	M	T	V	M	T	V	M	T	V	M	T	V	M	T	V	M	T	V	M	T	Shared	Recorded
C01	3	8	7	3	7	6	7	15	5	4	0	0	6	6	0	0	0	0	0	0	0	44	99
C04	5	4	2	4	5	2	4	3	6	0	0	0	8	7	3	6	10	8	3	5	3	20	113
C06	2	2	4	4	4	2	2	3	2	1	1	1	3	4	1	2	2	2	0	1	1	15	92
C07	3	3	5	3	5	3	0	0	0	6	5	2	6	7	1	4	3	2	0	0	0	19	63
C08	15	18	5	0	10	3	8	8	2	8	11	5	N/A			N/A			0	1	2	50	53

Table 5. Breakdown of the number of videos shared (V), comments from mothers (M), and comments from therapists (T) per week per mother. POST refers to the post-therapy programme deployment

5.3.1 *Moments Capture and Collection*

Unlimited Self-Collected Moments

KeepCam aimed to help parents to collect evidence of interaction that would facilitate more concrete discussion and reflection with professional and other carers. The mothers (n = 5) found data capture using KeepCam on their own smartphones very practical and straightforward. These devices were always to hand and ready to use (i.e. always charged), as one of the mothers noted: *"I made quite a lot of videos, but I did not always send them all. Making the videos was great fun and easy … Sometimes, I was trying to pick out the right one to send, or maybe I just needed to relax and send them all."* [C08]

Even though the therapist visit session was recorded on the therapist's Handycam (i.e. for clinical documentation), two of the mothers continued to set up and use KeepCam alongside the therapist's recording during the home visits. These videos were used as reminders or for in-session reflection, as C04 explained: *"The therapist would try and model some stuff, which*

we would sometimes video on the phone so that I could watch it back and remember… [or] we might watch it back together and go: 'Look, that is the moment that you can see that happening.'"

Although the therapist had confirmed to the mothers that 40 seconds was sufficient to capture a behaviour, the onus was still on the mothers to ensure that the right moment had been captured. The mothers were observed sometimes to capture and share multiple videos to show the full behaviour if it was not captured in a single video. In the initial trials, this might have been due to unfamiliarity with the new way of selective video recording, despite it having been introduced before the deployment. The therapist explained that *"I think that might have been the reason why they sent me multiple videos; because they had not quite got the 40-second bit that they want in one video, or forgot to press and extend the duration."* [T01]

Flexible Capture Settings: Anywhere, Anytime, and with Anyone

Various settings were used by the mothers to capture the moments in different situations and play scenarios. The mothers extended the recording duration for different reasons, including to ensure that they had pressed the button; to wait for a particular event to happen (e.g. the child trying to vocalise); or to capture the whole interaction moment when things were going quite well. The front camera was mainly used, since it was the default setting the mothers usually used. Also, it helped them to preview the scene and check the on-screen recording notification, as C08 commented: *"We tended to use the front camera because I wanted to be able to see when it was recording."*

The Bluetooth button was found to be easy to use and hide from the child, except for one of the mothers who forgot to use the button in the first trials. C06 explained her experience and said, *"I had it down the side of my [Laughter] leg, or if I was sitting I would have it in this hand or just down the side. It was not like, 'Oh, I will just pick that up,' so it was not in her face more so."* Meanwhile, the tripod was found helpful in placing the camera at a safe distance away from the child, so it would not interfere with play and allowed the mother to focus on physically supporting the child while playing. For instance, C07 commented, "*The little tripod we would often have on a windowsill or positioned next to the telly."* However, some outdoors or spontaneous moments (n = 25) were captured without using the button or the tripod. Instead of using the tripod, some of the mothers' partners or family members held the camera.

All of the videos were captured during normal play time, except for videos captured by three mothers who discussed how some spontaneous recording had been attempted, especially when successful communication happened. As C01 said: *"The one thing that we did often, by the end… We ended up not using the tripod, because [the child] might be sitting on my knee and said something. I would just think, 'Oh! I have got to get this recorded!'"* The play and communication time was explained by the mothers to be at any time during the day and was based on the child health and mood; for example, mealtime, bath time, or before bedtime. The videos were captured in various locations, including the child's home (i.e. in the backyard, kitchen, living room), a relative's home, or outdoors (i.e. in a public park or during vacations). Figure 16 and Figure 17 show example snapshots of KeepCam videos captured in different settings.

Figure 16. Snapshots from the KeepCam videos captured by the mothers at home in various settings; showing mother-child, father-child, relative-child, or the child alone

Figure 17. Snapshots from the KeepCam videos captured by the mothers in various settings outdoors, such as the backyard, a restaurant, or a park

Most of the videos showed the child with the mother. The exceptions to this were 54 videos recorded when the mother was holding the camera to capture the partner interacting with the child or to capture a spontaneous moment. This was confirmed by the therapists to be a useful

coaching mechanism beyond the visits for the other caregivers, to ensure complete generalisation and adaptions. T01 said, *"The mum was there behind the camera. She was making the videos, so they were all there, which is really nice, because that is what you want. You want a total – everybody doing that kind of stuff."*

Occasionally, other family members (i.e. siblings or grandparents) could be seen or heard in the video recordings. One of the mothers discussed her reluctance to capture other family members, saying, *"I have had to delete a couple of videos because the other one has come in and she is like – her head right in the corner. I am like, 'No. No. It is just really me and [the child].'"* [C06] The mothers (n = 2) also expressed their reluctance to capture videos when feeling challenged due to family circumstances, such as kids' noises or relatives' objection. As C01 said, *"My mum was here one day, and it was a nightmare, because she was so uncomfortable with being recorded."* However, some of the captured videos (n = 19) showed the child only. Therefore, mothers and therapists revealed that specific video capture set-up was not required, and videos can remain useful for reflection, as they commented on this:

"[The child] might be sitting on my knee or I would just think, "Oh, I have got to get this," and so I might just be holding the phone, doing it like that. So, we were not quite so strict with the criteria of us both always being in the frame, but it was just so nice to be able to share the good stuff that was going on, and I think that is really lovely, and often you do not get to do that with therapists." [C04]

"I knew that mum was behind the camera, so I knew that they were face to face. I would not say it was a negative thing. That is something to think about. It maybe does not have to be this fixed thing." [T01]

Adaptable and Less Distracting

Over time, it was apparent that less attention was being paid to the phone screen, as the selective capture technology became familiar to the mothers and they did not need to verify the recording status or preview the positioning after the setup. C07 noted that *"When we carried on using it, I would get more confident with not having to pay attention to it, or hiding the button, or whatever."*

Furthermore, in the first trials some of the mothers (n = 3) felt self-conscious about being recorded. As C01 said, *"It is hard not to look at yourself when you can see yourself. And I kept looking quite often to see if [the child] was in the right position and that would make me look again. But no, I did get more used to using it, I think, as the time went on."* However, in the later videos we observed that all of the mothers gained confidence about being in a recording: some of them were seen in their pyjamas (see Figure 17). For instance, C08 said, *"We felt relaxed with [the therapist]. It was fine. I think there is a big desire to do good stuff for [the child]. So, I do not really care what I look like for her."* The therapist also confirmed that and commented: *"I think they realise it is not really about them. It is not what they look like. It is all about what they are doing, and so it is not as stressful. I think just because you get used to anything. I think they got better at it."* [T01]

The children mostly did not notice the camera except when there was a notification, or after they lost their interest in the play. When they noticed the camera, we observed that some children shied away (1 out 148 videos shared) or tried to play with the camera (3 out 148 videos shared). For example, one of the mothers used to communicate to the absent therapist whenever the child noticed the camera, as the mother explained: *"She started to associate the camera with the therapist. So, she would start waving at the camera and I would say – 'Oh, what are you doing? Are you waving to [the therapist]?' ... then she would, sort of, wave, and then we would be able to get on with things, so it worked quite well."* [C04]

Implicit and Unforgettable

Four of the mothers reported that KeepCam made it easy to incorporate the video recording practice in their play session routine, as C06 said: *"I suppose you are playing and things anyway, I guess it is just a case of preparing the camera bits before you start."* According to the therapist, the mothers remembered to capture these videos without the need for reminders, which made the communication more organic and less intrusive. As the therapist said: *"I did not issue reminders, and I wanted to see how it would work. I wanted it to be a bit more organic. Will they ask for reminders? What will they do? I do not think they found it negative since they shared videos."* [T01]

The exceptions to self-initiated capture were hectic weeks; such as when the mothers were busy with their jobs or house building, or when the child's health condition was a priority. One of the mothers also discussed her frustrating experience when she failed to capture some

interaction moments due to the need for setup, saying: *"I spoke to [the therapist] about that and she said: 'How about setting it up and just recording it all then?' I thought about doing that and ... It felt a little bit like an intrusion of privacy, do you know what I mean? I did not want to be recording that and then my 12-year-old son come bursting in and saying – 'Oh Mum, where are my trousers for school!' Which probably would happen. So just leaving it to record was a bit difficult, as well."* [C01]

Similarly, most of the mothers (n = 4) felt no need for reminders since video capture was organised within the play session. The exception was one mother who reported, *"Some weeks were plain sailing and other weeks it was more difficult, and we had to almost remember to have a camera on."* [C07] Moreover, one mother captured more spontaneous moments and found that the reminders feature was not appealing to her, saying, *"Reminders are good, but sometimes it is just, kind of, like – 'Ah, I am trying. Ah, [I will capture this] you know?'"* [C08]

5.3.2 *Parent-Led Coaching Experience*

Sharing What, When and with Whom

KeepCam was used as a tool to facilitate the sharing of videos to access remote support. All the mothers and the therapist were positive about the experience of coaching through video sharing and mentioned the simplicity of sharing using KeepCam. For example, C04 said: *"I was really impressed. I thought they were simple ... I just thought the simplicity of it made it really good, and I wish we could do it with more of our therapists. Like, showing the physio or the OT. I often catch [the child] using her left hand, which she struggles with so much, and she will not always do it in an appointment, but she is doing amazing things without even thinking about it, and I would just love to be able to share that."*

Additionally, the therapist found the mothers comfortable with sharing at any time, remarking, *"Sometimes I would maybe get a message at nine o'clock at night on a Sunday."* [T01] As expressed by the mothers and observed in the videos shared, there were several reasons for sharing. These included demonstrating skills; seeking feedback/reassurance on a practice; seeking advice on new experiences; verifying the child's communication pattern; and showing frustration, achievement, or funny events. Moreover, the mothers managed to select the video that showed full behaviour, as confirmed by the therapist. However, some

mothers (n = 2) indicated that the video selection required re-watching to confirm the correct videos to send, as one said: *"Say I had taken 15 or 10 videos out in the garden, in the swing, and then you look at the app on your phone, they all look the same."* [C01]

Furthermore, one mother stated that she used to share multiple videos when the behaviour was not captured in a single video or when she could not decide which video to send to demonstrate the strategies. Beyond the therapist-mother communication, some of the mothers (n = 3) shared the videos with other carers in order to explain practices or show achievements. One of the mothers said, *"I did share some of the examples that we did on the KeepCam, particularly with my husband and with our nanny."* [C06]

Accessing Support and New Communication Behaviours

The mothers (n = 5) found that they had no issue with conveying comments or questions in an informal but informative way (e.g. using emoticons). As C01 expressed, *"In a message I talk the way that I would talk anyway, and I do not try to make it too informative. I like it to be informative, I do not feel that it needs to be formal or anything at all."* As observed, the mothers' comments involved reflecting on the adult behaviour, providing further details about the interaction, reflecting on the interaction, or suggesting new strategies. For example, C04 messaged the therapist, saying, *"Since your last visit [the child] has been very deliberate about making eye contact and signing for help. She remembered the context of the book and asks for help immediately, sometimes without attempting it herself! I hope that looking for joint attention in other contexts will come so quickly."* Labelling behaviour was noticed: some mothers (n = 2) attached less semantic text such as *"Here is another video"* [C07] in order to send the video, which consumed additional therapist time.

Moreover, the therapist sometimes asked the mothers to clarify the interaction scenario or to explain more details beyond the video timeframe if the captured segment was not detailed enough. For instance, one of the therapist comments said, *"Great waiting for [the child] to take a turn! He looks like he is sharing really good attention with Dad. Interpreting his sounds as responses to your questions will help [the child] understand that you are interested in his responses and encourage him to keep communicating. Does he respond like this consistently when you wait?"* Furthermore, as observed, sometimes the therapist responses involved referring to previously shared videos or sharing videos themselves (shown in Figure 18). As the therapist explained, *"The mother said, 'We have just discovered this new word*

today. Can you send me the sign for it?'… That was the only video reply I did, for the sign, because I cannot do that in a text." [T01]

Generally, the therapists' responses and the remote support were aligned with reassurance, guidance, praising success, identifying child motivations, encouraging persistence and repetition, and provoking thought to build on or tweak practices. The mothers (n = 5) believed that the feedback was never discouraging or judging, as C06 said: *"It never felt onerous, or like we were not doing a good job, or anything like that."* However, the therapist wrote the feedback carefully; *"You do not want to give them a massive amount of information… So, I think that was a bit tricky, trying to get the kernel of what I wanted to get across into a short message."* [T01]

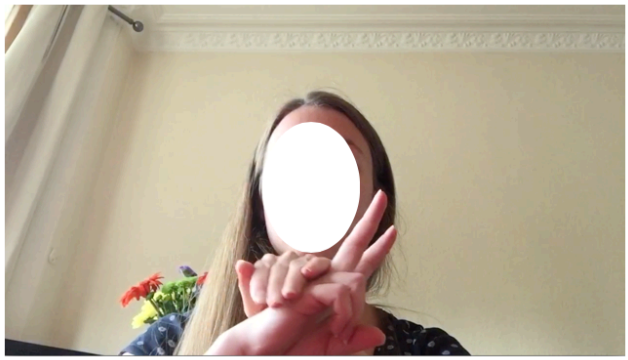


Figure 18. Video reply captured and shared by the therapist to show a sign language

Impactful Continuous Contact

The mothers (n = 5) did not expect immediate responses and showed their understanding of the therapist's busy routine, as C06 stated: *"I would not expect her to drop everything and get back to us straight away anyway."* The average therapist response time was one day, as T01 noted: *"I think I would want to give them a response as soon as possible, because I wanted to create a dialogue throughout the week that we were not in touch."* From the mothers' perspective, the continuous remote contact was appreciated; compared to a home visit, but with more concrete discussion over realistic visual examples that kept them motivated, engaged, and looking for progress and opportunities. As one mother said, *"You are in constant contact and if there are any questions we can contact [the therapist]. We have seen a huge difference in [the child]."* [C07]

The continuous conversations between visits were perceived as valuable by the mothers for deepening their adaptation of strategies and keeping that discussion going. One of the mothers expressed her interest in synchronous communication: *"I would notice when she was on, so I would send her something straight back and make the most of that time."* [C04] With the open communication channel, the mothers were able to ask their questions before forgetting (n = 3) or correct the other caregivers' practices based on the therapist's observation (n = 1). Furthermore, some of the mothers (n = 3) found it useful to review to the conversation messages repeatedly, as one said: *"I would have a quick read, and then on the night when I got in I would have another read to make sure I have read it or done it correctly."* [C08]

From the therapist's point of view, the continuous conversations were valuable to deepen the relationship with the parents, understand the parent's learning style, understand the child's context and environment, provide an opportunity to clarify the description of practices, and use the video as material for assessments. Similarly, the therapist found that video sharing prompted the parent to keep practising in a less stressful way. A mother confirmed that *"[The therapist] was always very understanding, if I said, 'Oh we have just not managed much this week,' then yes we could."* [C08]

Independence, Expansion, and Monitoring Opportunities

Additional coaching values and opportunities were observed with the remote parent-led video coaching techniques. Video recording and sharing facilitated prioritising and fitting the practices into the mothers' daily routines with the continuous support, and the mothers found themselves more engaged and committed to the home practices. As C08 reported, *"It is easier to engage when you have got somebody coming and with the app you are in constant contact and if there are any questions we can contact them."* Additionally, due to the need to capture the interaction without external distractions, one of the mothers discovered the demand to have a focused one-to-one therapeutic playtime with the child. As the therapist explained:

"She had, obviously, the other child, and her life is a bit hectic at the moment ... But a positive thing that came out of it was that she was saying that she was splitting the boys' days at nursery, so she will actually have an afternoon when she is just with one of them, which would be really nice. It is nice that it is given her that kind of – 'Oh, maybe I do need to spend a little bit more time just with [the child].'" [T01]

Moreover, the ability for the therapist to see the child's interaction in their natural environment was perceived as valuable for therapeutic coaching, as C07 said: *"She will see him in the environment that they are not going to be able to see."* Or for how the caregivers adapted therapy practices in different routines, as C04 said: *"Just by having those little bits of video, it shows where we are fitting in therapy into a real life, not just the appointment."* Additionally, this visual information facilitated the development assessment and session planning, as T01 said:

"The videos they would send that week would be the basis for what I was going to do in the intervention, because it was like a nice assessment of what they were doing. So, if there was something that was not working, then I would know what to move towards. If they had not really understood that instruction, this is what we will do next. So, I used the videos all the time."

Expansion of therapeutic practices and adaptation by the children's other caregivers was another observed outcome. In one of the families, the partner was actively involved in the therapy practices and sometimes shared videos instead of the mother, as explained by T01: *"Because he could not be there during the visits, he really wanted to be involved, and so they both wanted to learn. So, the mum was there behind the camera making the videos, so they were all there, which is really nice, because that is what you want. You want a total – everybody doing that kind of stuff."* The remote coaching application was also used by the therapist for remote monitoring and assuring consistent home practices, as T01 noted: *"You want to see them doing it consistently, I suppose. Because that is what we are looking for, as therapists – that they have learned something, and they can use it again and again."*

5.3.3 *Impact of the Frequent Parent-Delivered Therapy*

Condensed Therapy Experience

The parents had the KeepCam as a tool to communicate and gain support in the home activities. In general, the therapist found that the parents appreciated the therapy protocol, having more frequent visits, as C04 expressed: *"The frequency, having it every week was amazing. You cannot say anything else than having somebody with you."* The mothers found weekly visits valuable in different ways; for example, as a condensed way of learning, for recognition of faster progress, better child-therapist engagement, and visits more focused on

planning techniques rather than on exploring the communication environment. The therapist noticed that the children started recognising her and engaging more with the therapy practices during the visits, while the mothers seemed more relaxed and comfortable while working as a team, compared to their behaviours during the initial visit assessment.

The mothers (n = 5) found that the introduced therapy strategies (see Table 3) were not too prescriptive but were personalised, easy to fit with their own ideas, and easy to follow with the support of the provided strategies sheet. The mothers (n = 3) reported that having a clear outline of how their children were following a specific pathway encouraged them to act, to see progress, and reduce the children's frustration to communicate. While one mother realised that there was no pressure if her child was not engaged during the visits and that the focus was more on coaching the mother, nevertheless she found other therapists' visits very pressurised. Also, the mothers (n = 3) found the coaching helpful to discover the importance of repetitiveness and discovering new ways to communicate, as one noted: *"We like the parental coaching side because you do not think of things until somebody actually says to you – 'Have you thought about doing stuff?'"* [C08]

Moreover, the therapist discussed how with the short duration between visits, the mothers might feel pressure, be apologetic, and rush to practise and share videos; thus the coaching dialogues were sometimes missed. The therapist also commented on the dependency of visits on the parent-child progress, saying, *"If there had not been a massive amount of change, and we were just going over what we were doing, then you do not want to be there for too long."* [T01] Furthermore, two of the mothers expressed how the weekly appointments were sometimes overwhelming due to family commitments. With the existence of remote support, the mothers and the therapist suggested that frequent visits in bursts would help the child to improve, since some children are very slow in development and regular contact reduces the need for weekly visits. The mothers suggested:

"I mean because it was only for a six-weeks period it was fine but, you know, we have a lot on generally – hospital appointments, I am also working, and other therapies. So weekly maybe would become a bit too much if it was constantly weekly but for six weeks that was good. It is quite difficult because things can only move as fast as the child is moving ... It was good, but there probably would not need to be as frequent visits, particularly when you are having the contact during the week as well with suggestion." [C07]

"Once a fortnight, I think that is enough time in between to try the strategies. I think you would see some kind of improvements from a therapist point of view, you would be coming out and actually seeing some progress … The issue being is if you are a working mum and a busy family and stuff like that. So, it would be nice to tone down the appointments, so once a fortnight would be good." [C08]

Commitment and Improvements

The therapist noticed how the mothers' skills had improved compared to the initial visit assessment. The therapist explained their coaching role and the importance of the mothers' engagement, saying: "*The fact that the kids have developed is testament to the parents really having taken everything on board … It was meant to be a bit of a two-way dialogue, you are looking for them to be practising the skills, so you give them reassurance that they are doing what is a good idea. Maybe giving them a little suggestion how to increase it, or move it onto the next bit, and then maybe asking them a question, so that you get a better response, or maybe just seeing if they just take that on, and the next time you see a video, they are doing it."* [T01]

Although the intervention time was too short for children with slow development to see substantial improvements, the therapist reported that they noticed small interaction changes compared to the baseline assessment of the children. As T01 said: "*There was not a significant improvement, but there was an improvement, like no one decreased, which is always good, and no one stayed the same. There was also improvement in just how the mothers were interacting with their child."*

On the other hand, all the mothers confirmed that they noticed improvements in their children's interactions, such as eye contact, copying others, selecting from choices, holding attention, more words coming out or a variety of sounds, or more sophistication in vocalisation. Moreover, in one of the reviewed videos we observed a mother's excitement after capturing the child vocalising for the first time. Some of the mothers (n = 2) noticed some improvements through KeepCam videos while self-reflecting. For instance, C08 commented: *"We actually picked on a couple of words he started, while we were going through the app… it was the first time that he had said, 'Yes.' It sounded like 'Aye,' but we caught that on video and I probably would never have noticed that if I had not have caught it on video at that point."*

Commitment to practices and access to support was perceived by the mothers (n = 4) as the reason behind the children's skills improvements. As C01 said, *"He seems to have had a massive improvement all of a sudden. All of the summer he plateaued pretty much. And one morning he got up and had about five new words in that day ... But because I was concentrating on it, there was definitely improvement in how he behaved. The interaction was definitely more."* However, one of the mothers had higher expectations that were not fulfilled: *"I mean I could see improvements and that he was making progress, but I suppose I just want him to make large, big progress. The progress steps were probably just really small."* [C07]

Post-Therapy Adoption and Reflection

After the six weeks of weekly visits, all the mothers reported adopting the learned practices in their daily interactions with their children, and some of the mothers (n = 4) were referring to the materials produced (i.e. videos, messages, programme sheet). The mothers (n = 3) referred to the *Communication Toolbox* sheet to look at the strategies again as a reminder, as C08 said: *"The strategies I have had a little look at again just as a reminder."* The messages on KeepCam were also used by the mothers (n = 3) as reminders, or to reflect on the child's progress. As C07 said, *"I have a look at the videos and the comments just to see if – just for myself really to see whether his progress was, kind of, beyond that or whether we were still, sort of, at that level, if that makes sense."*

Similarly, the videos were found by the mothers (n = 4) to be useful for self-training and reflection on the child's progress, as well as sharing with others. For example, C06 reported that *"I was speaking to somebody the other day and I was like, 'Oh look at this video of [the child].' Possibly to refer back to how she was and how she is now, to see how much she has come on."* The practice sheets and videos were also found useful by the mothers (n = 4) for sharing the personalised practices with other carers (i.e. partner, nursery, nanny, grandparents) as an update after the therapist's visit or as a demonstration of new techniques to try. Additionally, it was observed that some of the mothers (n = 3) remained engaged with using the KeepCam and seeking support from the therapists after the deployment phase (see Table 5); either through conversations only (n = 2) or along with video sharing (n = 1). For instance, C04 shared videos along with a comment saying, "Sometimes. I know she is trying to tell *me lots through signing and vocalising, but I think my understanding is limited! Here is some chat from today."*

5.4 Discussion

The goal of the KeepCam deployment study was to explore the participants' engagement with the parent-led remote video coaching design to access the needed support for the indirect therapy programme. Coaching is an interactive relationship that is coachee-focused and less driven by professionals (Olsen 2014; Allen & Huff 2014). Rather than educating individuals, the remote indirect therapy programme was designed by the therapist as a continuous coaching process to promote self-observation and reflection, to stimulate the parents' abilities, and to support the children's development in their own environments. The design of KeepCam indicated that the main health coaching attributes (Olsen 2014), of demonstration, reassurance, guidance, validation, encouragement, and motivation, can be achieved remotely. In this filed study, the video capture and sharing technology introduced a new parent-led approach that leveraged the parent role in the indirect therapy programmes and delivered support between the therapist visits.

In the following sections, we discuss the implications of these findings in relation to the design goals (described in Chapter 4) and related literature, as well as considerations for designing remote support technologies in the context of indirect therapy. The design features are not specific to this type of speech and language therapy, but feasibly overlap with other home therapy services. Thus, the design considerations highlight opportunities, barriers, and insights that can apply to other remote coaching solutions.

5.4.1 *Flexible Models of Therapy*

Several technological solutions have targeted expansions of the service delivery model or facilitating assessment (Cason 2011; Green et al. 2010; Marcu & Hayes 2010). However, in KeepCam, we introduce a model of service delivery that is more flexible, parent initiated, provides regular support, and facilitates the adaptation of therapy practices in everyday life. This therapy model ensures continuous motivation and support for the parents between therapist visits (DG1, DG4). The pilot deployment study provided an intensive therapy programme, involving a weekly visit combined with voluntary technology use between visits, based on needs. Although the therapist did not enforce the weekly video sharing, the mothers relied on the technology to prove their commitment to home therapy and seek confirmation on practice correctness (DG4). Consequently, KeepCam represented an external drive to keep the mothers motivated; it encouraged them to identify more opportunities and fit the therapy practices into play routines with their children. Recurring practices represented an important

element in the coaching process (Olsen 2014; Rush et al. 2003; Pickles et al. 2016); with the therapist's support, the continuous contact reinforced this repetition. This progressively improved the mothers' skills remotely, with no need for face-to-face contact. Although the weekly visits were found to be useful, the mothers with slow-developing children found them stressful due to the lack of child progress. The therapist also indicated that these visits were not needed if there was no new stage to introduce, based on the parent-child progress. Consequently, with the signs of unnecessary therapy visits, we concluded that more support was needed to facilitate generalisation and adaptation, rather than more therapy visits. Thus, the remote coaching technology can facilitate the monitoring of mother-child interaction and planning of home visits based on the developmental trajectory, the progress of the child, and struggles encountered.

This parent-led technology has the potential to facilitate greater support for mothers through an informal asynchronous communication channel with professionals. However, the remote continuous support channels were found to be associated with some challenges, including the amount and tone of information communicated, labelling behaviours, and the importance of rapid responses to maintain the level of engagement with practices. These challenges uncovered an additional burden on the professional side; remote support has been confirmed to consume the professionals' time in previous work – e.g. (Hayes et al. 2014; Kientz et al. 2009; Kientz & Abowd 2009; Kientz, Arriaga, et al. 2007). Thus, to balance the benefits of continuous support with the burden implied on the therapist, further design opportunities can be applied to visually communicate feedback and facilitate communication coordination.

Furthermore, mobile communications were not considered to be a substitute for physical visits (Cason 2011). However, KeepCam represents a digital solution that was found to help the mothers to be more self-reflective, to promote their confidence, and to refine their skills to support their child's development. It also helped the therapist to plan a more realistic visits programme that fitted their routines (DG5). Self-reflection can also allow reviewing of the impact of the current therapy practices and promote the adoption of new techniques (Rush et al. 2003). Additionally, video interaction guidance has proved its potential in the coaching process for self-learning and reflection (Balldin et al. 2018), and the design of KeepCam has shown the feasibility of direct coaching during the visits to generate short snapshots for more concrete face-to-face discussions. Moreover, there are opportunities for technologies to facilitate peer collaboration within these contexts. Parent communication group sessions are

seen as an alternative way of parent training (Baxendale & Hesketh 2009); hence video-coaching technology could has the potential for peer-to-peer supportive reflection, where peers can review and comment on their individual videos remotely between the group sessions.

5.4.2 *Empowering Families*

Coaching is initiated based on the desire for improvements (Olsen 2014) and requires commitment from the parents to activities that lead to improved children's skills (Rush et al. 2003). With KeepCam, the mothers were able to drive the ongoing coaching process and develop their skills (DG5). The therapist allowed the mothers to lead, while focusing more on awareness and a progressive therapy plan. Many data capture and access tools have shown that self-reflection can lead to a sense of empowerment (Tang et al. 2012; Li et al. 2010); the mobile video coaching facilitated the families' sense of empowerment in different ways. Initially, the remote coaching and video sharing was voluntary and dominated by the mothers, based on their needs. The mothers had full control over which videos to share; they also had the ability to initiate and visually share practices/challenges as well as to request visual illustrations for specific practices. Additionally, personal discovery and accountability were indirectly facilitated through video coaching, and the mothers were able to identify the need to concentrate more on the therapy practices to achieve progress.

Moreover, a collaborative relationship was established between the mother and therapist as a result of the continuous communication and reciprocal observations, with the focus on a common goal to promote the mother's skills and the child's development. This is consistent with the essential elements of family coaching (Allen & Huff 2014; Rush et al. 2003). Olsen (Olsen 2014) discussed how this mutual relationship enables sharing of powers and abilities. Through the familiar communication interfaces (DG4), KeepCam facilitated continuous video-based dialogue between the home visits. Consequently, a trusting relationship was established, and the mothers were less anxious and less formal, which created more open communication with the therapist and reduced the mothers' isolation. Ultimately, the mothers gained the ability to influence the coaching process; they recognised their expertise and shared their experiences with other therapists, relatives, and caregivers (DG5). The importance of the self-conception of the caregivers as experts has been discussed in various caregiving contexts (e.g. (Schorch et al. 2016; Mamykina et al. 2008; Nazneen, Rozga, et al.

2012). It is considered a crucial element of the coaching techniques designed for home therapy programmes (Baxendale & Hesketh 2009; Green et al. 2010).

The mothers built on their independence and explored further social support by acting as communication conduits between therapists and other carers. The mobile video capture allowed the mothers to instantly capture and share achievements, as well as to demonstrate new practices and coach the other caregivers. Therefore, KeepCam provided the ability to promote confidence, skills, and capacities, which are central elements in coaching theories (Olsen 2014; Allen & Huff 2014). One possible design improvement to facilitate and simplify the video sharing between the caregivers would be to create a shared repository of videos with appropriate access permissions. However, the capabilities of self-reflection and self-recognition of expertise need to be sustained beyond the intensive therapy programme and visits. Initial insights from this study confirmed the interest in continuous engagement with the remote support technology after the deployment period; however, further exploration is crucial to design for self-coaching and long-term adoption. Designing for social support with senior experienced caregivers may reduce demand for frequent professional support, reducing the reliance and the time burden on therapists.

5.4.3 *Ubiquitous Data Capture*

Previous studies have confirmed the importance of video capture in reflective practices. It shows real interaction alongside the context, without any misperception or miscommunication, which would be the effect if this information was communicated just verbally or in a written form (Stokes & Cummins 2013; Hayes et al. 2008; Nazneen, Rozga, et al. 2012). In our study, KeepCam verified the importance of the naturalistic videos captured for more concrete therapeutic reflection, based on the selective interactions captured. The designed technology used a smartphone as a convenient device that allowed video capture focused on specific moments that the parents were willing to communicate for reflection (DG1, DG3). The use of the personal mobile devices of the mothers made the video capturing experience more adaptable for them. Interestingly, prior studies have shown that families experienced with developmental delay were more frequently capturing videos (Kientz & Abowd 2009). Our field study results show that KeepCam enabled the parents to capture multiple interactions in different places and settings; interactions which progressively became more focused on the children and less self-conscious (DG2). The short duration of the videos recorded showed the potential to facilitate coaching, since further reflection from the mothers

was required beyond the recorded timeframe. Additionally, the study revealed that different recording setups (e.g. videos with the child only or with other caregivers) were suitable for the therapist's analysis, which made the recording requirements less restrictive for the parents.

With the captured data, the therapist was able to establish a better understanding of the parent-child interaction in their natural environment, and the mothers were able to see progress and identify the small improvements in the children's communication skills, either while recording or while reviewing these moments (DG5). Given the overwhelming care routines facing the mothers of CP children and the limited time of therapists, the selective video capture technique was designed to minimise disruption (DG2). The field study showed that the mothers easily integrated the mobile data capture into their existing play practices without the need for prompts or reminders, and with minimal intrusiveness. This is in contrast to previous data capture methods based on fixed or semi-portable recording devices (Kientz et al. 2009; Hayes et al. 2008; Nazneen, Rozga, et al. 2012).

Overall, KeepCam addressed these requirements and revealed further scope for improvement. The mothers managed to set their smartphones out of the children's sight, yet future design consideration should emphasise the need to make the video capture process even less visible, for example by using a subtle vibrating button as a recording confirmation (instead of the beep sound and flashing screen as a notification). The mothers found the retrospective video recording a new experience; when the short clips were saved or extended with a button press, they were relying on the notification to confirm this action. However, after a few trials the mothers managed to use this way of recording, with less attention given to the notifications over time. Ensuring that the right moment had been captured was another data capture challenge faced by the mothers, which resulted in them sometimes capturing multiple videos. The ideal video duration (~1 minutes), suggested by the therapists, might have contributed to the challenge of recording moments, as the mothers might have missed pressing the button to extend the recording. Therefore, future deployment trials can investigate if the issue was due to unfamiliarity with the technology, other external factors such as anxiety about missing moments. Moreover, alternative capture strategies can be investigated where the full interaction recorded, and the remote button used to mark specific moments for post-recording review and editing (Hayes et al. 2005; Kientz & Abowd 2009).

5.5 Summary

Parent-delivered home therapies can place an overwhelming burden on mothers as a result of the less frequent home visits and professional support. Therefore, an added burden is placed on the mothers in which they have to manage the complicated caregiving responsibility for children with CP as well as adopt therapy practices to promote their children development along with maintaining their collaboration and communication with the caregivers' network. The eSALT case study presented a design process to engage the mothers of children with CP in the design of digital solutions to meet and balance their needs with the professional therapists needs (related to RQ2). In Chapter 3, we provided an in-depth contextual exploration of the existing challenges and experiences facing the mothers and therapist in the indirect therapy context (related to RQ1). Throughout the co-design phases, we generated the design features for a parent-led digital support technology (Chapter 4), and then reflected on these features based on the way the mothers and the therapist engaged with the technology in a real field deployment setting (Chapter 5). We highlighted the potential opportunities for parent-led coaching solution to alleviate some of in-home practices challenges which were not the focus of previous work in the context of remote therapy coaching (Hwang et al. 2014; Aggarwal et al. 2015). As a result, we discuss the opportunities for a responsive model of therapist support for home therapy programmes, in which families are more empowered (related to RQ3).

Although the eSALT case study suggests directions for designing technologies to be used for indirect SLT for children with CP, there are many remaining opportunities to be investigated. Such as, how the captured videos can be used for feedback and reflection to promote the parents' skills, how the resulted flexibly model of therapy can be used with early SLT programmes for other disorders, and how can other models of data capture and sharing fit the parents and therapists needs. Therefore, in the next case study, ePACT, we further investigated the data capture and support needs in the context of early SLT programmes for children with autism.

Chapter 6. Contextual Exploration of PACT

6.1 Introduction

The eSALT case study consolidated the design considerations for coaching technology to support indirect therapy for parents of children with CP. eSALT study revealed that indirect therapy was affected by the matters of stress, loose management, and lack of support. To meet mothers' needs and professionals' practices, we proposed that parent-led coaching technology should be designed to enable ubiquitous data capture, self-initiation, and management, while maintaining access to the different social support channels. The field deployment outcomes from the eSALT case study guided our interest in looking for expanding the design considerations to other forms of indirect therapy and to further explore the role of videos feedback for self-reflection. Therefore, in this chapter, we further investigated the support and data capture needs in a second case study of indirect programmes for children with autism.

Despite our early focus on indirect speech and language therapy for children with cerebral palsy, similar home therapy approaches are practised with preschool children with different conditions, such as Autism Spectrum Disorder (ASD) (Diggle et al. 2003; Diggle & McConachie 2009; Green et al. 2010). Autism is one of the neurological developmental disorders that affect language, communication, social, and behavioural abilities (Green et al. 2010). It is estimated that 1 in 100 children in the UK has autism (Lloyd 2012), 1 in 59 children in the USA has autism (CDC 2018), and around 1 percent of the population worldwide has been diagnosed with autism (CDC 2018). Autism is considered a lifelong disorder, and studies have shown that ASD can be diagnosed at age 2 from the impairments in social communication (Charman & Baird 2002; Chakrabarti & Fombonne 2001). The autism spectrum is wide: children can experience different scales and levels of difficulties in their communication and social skills. For example, children with autism may have difficulties in perceiving or initiating language or social cues; they may also show intense concentration, odd interests, or repetitive behaviours (Diggle et al. 2003). The importance of early therapy interventions for children with autism for improving their developmental skills and reducing the severity of symptoms in adulthood has been supported by various studies (Lord et al. 2005; Rogers & Vismara 2008). Similarly, for preschool children, these early interventions are parent-mediated to promote parent skills and support the autistic children's development

through parent training and continuous practices in their daily routines (Diggle et al. 2003; Diggle & McConachie 2009; Green et al. 2010).

In 2016, one of the early SLT designed for preschool children with autism clinically proved the effectiveness of intensive early therapy programmes to reduce long-term autism symptoms (Pickles et al. 2016). This therapy was called the Preschool Autism Communication Therapy (PACT); it ran between 2006 and 2010 (Green et al. 2010). Six years after the original intervention, a sustained improvement was identified in the parent-child interaction and the child autism symptoms (Pickles et al. 2016). The PACT intervention was a collaboration between the University of Manchester, the University of Newcastle, and the Institute of Child Health in London. Based on the eSALT study outcomes, we were invited by the lead PACT therapists to discuss the design the KeepCam technology. As a result, we discussed our interest to expand the design outcomes of video-based coaching technology in the context of PACT and explore ways to promote parent self-reflection skills. PACT was an opportunity that met our agenda to generalise the design of the indirect therapy coaching technology in other therapies, and to investigate different ways of engaging mothers and therapists in the design process.

Therefore, the ePACT case study aimed to investigate the support needs in the context of indirect therapy delivered to parents of children with autism and inform the design of self-coaching solutions through the design process with parents and therapists where they could be more creative and critical. In this chapter we focus on describing the PACT therapy protocol and the design-oriented approach adopted throughout the ePACT study, as well as presenting the results of the initial contextual understanding of current practices and existing challenges.

6.2 Preschool Autism Communication Therapy (PACT)

PACT is an early speech and language therapy designed for preschool children with autism, aged between 2 and 5 years (Pickles et al. 2016; Aldred et al. 2011). The protocol principles were derived from the fundamental principles of early speech and language therapy (Majnemer 1998; AAP 2011; Pepper & Weitzman 2004). The main focuses of the intervention are to facilitate joint parent-child interactions, improve communication, understand the child's intentions, and develop language skills. As in early SLT, the PACT programme is an indirect therapy that is focused on training the parent to improve the parent-

child interaction, which subsequently helps to promote the child's communication skills. The training goal is to adjust the current parent-child interaction to match the child's individual level of communication and motivate the parent to continuously use the adapted interactions in their everyday communication with their child. The therapy is based on the existing communication practices of the parent with their child, assisting the parents to recognise the child's communication signals, correctly interpret these signals, and respond to them timely and contextually.

The PACT programme is a framework of staged protocol that utilises the video interaction guidance principles (Kennedy et al. 2011). As a video-aided intervention, the guidance is provided based on recorded parent-child play, followed by a reflective feedback session. The parents are encouraged to lead the feedback session by identifying successful interaction moments, reflecting on what made these moments successful, and then agreeing on specific and individualised goals or strategies to adopt in order to repeat and extend these moments. The therapist facilitates the reflective feedback session by asking questions to guide the discussion; to help the parents to identify the good moment, the parent action, the child response and the reason behind their response.

Furthermore, PACT protocol consists of six stages of the communication development hierarchy. The stages are developmentally sequenced, beginning with "establishing shared attention" and ending with "expanding language and conversation". Each stage focuses on specific communication aim and involves a set of strategies to adopt in order to achieve the stage aim. The strategies are the practices suggested to the parent in order to change their existing interaction behaviours, e.g. with "Mirroring" strategy the parent copies the child's words/sound/action at the same pace and intensity in order to achieve the stage aim to establish a "Joint Attention". (See Appendix D for PACT stages and strategies). All the parents start from stage 1, and the therapist progresses the parent on to the next stage based on the parent's adoption of the strategies and the child's development level.

The PACT programme lasts for a year and consists of two phases: a six-month treatment phase with fortnightly therapy visits, and a six-month maintenance phase with monthly visits. Each visit lasts for 90 minutes and structured as follows: progress review, video captured, video feedback, and goal setting. During the visit, and after discussing the progress from the last session, the therapist asks the parent to play with the child; the therapist then records their

interaction for 10 minutes. Then, the parent and the therapist re-watch the video together and start the reflective discussion, focusing on the positive interaction moments. The session ends with setting therapy goals and strategies for the parent to practise at home for 30 minutes daily before the next therapy visit. At the end of the PACT programme, the therapist provides the parent with a summary programme of the successful strategies to keep adopting repeatedly.

A variation of the PACT programme is called PACT-G; that is, G for Generalised (Green et al. 2015). PACT-G is designed for children with autism aged between 2 and 11 years, as an extended version of the PACT protocol with added elements to facilitate generalising the adaptation of the principles across the various contexts surrounding the children. Thus, in addition to the parent training, similar training is provided separately to the child's learning support assistant in the school. In the PACT-G programme, remote video chat sessions (i.e. using Skype) are used to replace half of the face-to-face sessions. The remote sessions replicate the format of the face-to-face sessions. However, instead of capturing the video during the remote session, the parent/teacher is asked to capture 1–2 minutes video clips from the home/school setting and share them with the therapist in advance of the session. Consequently, the remote session is focused on reflective review of the video shared and therapy goals setting. Figure 19 and Figure 20 below summarise the session format of both the face-to-face and remote sessions.

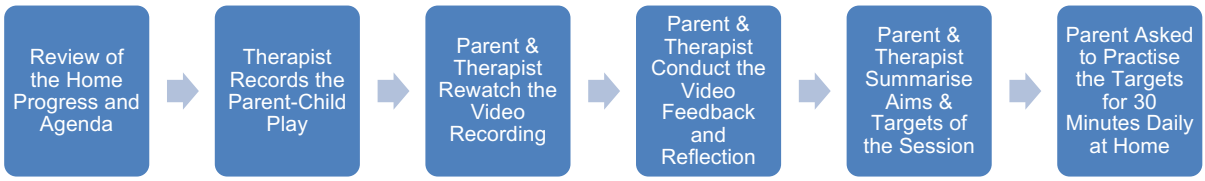


Figure 19. PACT Face-to-Face Session Format

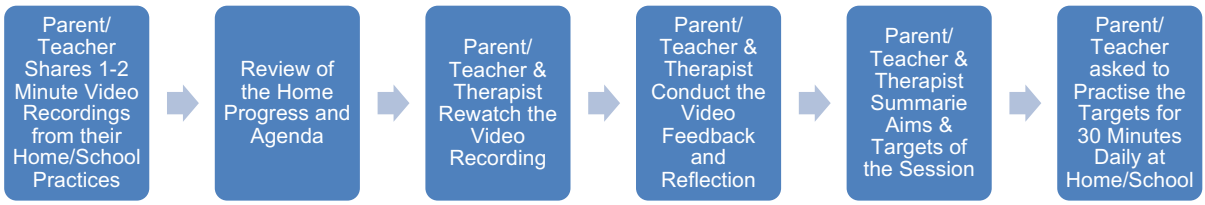


Figure 20. PACT Remote Session Format

6.3 Methodology

6.3.1 *Ethical Approval*

The ePACT study involved a series of design sessions with PACT therapists and parents who had experienced the therapy intervention. Thus, the ePACT study was approved by the Newcastle University Ethics Committee. Invited participants were given a verbal information and written information sheet to explain the research aim, participant role, collected information, forms of the data captured (audio recording or photos), research phases, expected outcomes, and the data protection measures. Participation was voluntary, and it was explained that they could withdraw from the study at any time and that any information collected would be deleted. Participants were assured that their decision to reject the invite or withdraw from the study would not affect any services that they were currently receiving or might receive in the future. The participants received a copy of the information sheet, along with a consent form to complete, sign, and return to us by mail before the first workshop.

Prior to the first workshop the parents were invited to share a sample of their personal video recording of a play session with their children. A video sharing invitation was provided via the information sheet, which was combined with the consent form to sign and return to us if they accepted. It was explained that these videos would be used during group discussion sessions with the parents and the therapists as examples to see how to mark the interaction and reflect on the video using PACT principles. Confidentiality measures were explained: the videos would be stored on the researcher's password-protected computer held at Newcastle University, video files would be deleted at end of project, and if they accepted then their files could be shared via Newcastle University's File Drop-Off System.

6.3.2 *Participants and Recruitment*

The aim of the ePACT case study was to establish an understanding of the PACT experiences in real context and design digital solutions to promote the parents' self-reflection skills. Thus, we required participants who had experience with the PACT therapy, had basic technology literacy, and were willing to take part in this design study. We aimed to have therapists and parents participate in the ePACT study in order to establish a comprehensive perspective on existing practices and potential digital solutions. Participants were recruited to the study through the existing PACT network and outside of National Health Service channels. Recruitment was open to the PACT sites from Newcastle and Manchester. We managed to

recruit a total of six mothers of children with autism and four therapists. As confirmed by the PACT team, the majority of the parents involved in the PACT therapy programme were mothers, and only rarely fathers. Additionally, for the last design session we recruited an additional therapist to replace a therapist on maternity leave.

Four of the mothers were from Manchester and two from Newcastle. All of the mothers had been involved with the PACT therapy programme for 4-6 months, while their children had been diagnosed with ASD when between 2-3 years old. Three of the mothers had a Skype session part of their PACT programme, one opted out from the Skype session due to her lack of experience with technology, while two mothers did not have the Skype session option since it was not allowed in the Newcastle NHS Trust. However, where Skype was not possible, the therapists used the format of a Skype session but delivered it face-to-face in the parent's home; that is, they used the videos the parent had taken and sent them ahead of the session as the basis of discussion and feedback. (see Table 6 for the mothers' experiences with PACT, and Table 7 demographic data). Three of the mothers were working, while the rest were full-time carers at home. One of the mothers stated that she quit her job due to her childcare responsibilities. All the mothers were married, and the fathers were working full-time, except one who was a carer. Three of the parents (mothers and fathers) held undergraduate degrees, three of the parents held postgraduate degrees (two Masters and one PhD), two of the parents had a National Vocational Qualification Level 3 qualification, and one parent had only completed secondary school; the remaining three parents left school before completion.

ID	Experience with PACT	Involved in remote sessions?	Highest PACT stage achieved
P01	6 months	N	5
P02	6 months	N	5
P03	4 months	Y	2
P04	5 months	Y	3
P05	5 months	N	3
P06	4 months	Y	6

Table 6. Profiles of mothers' experiences in PACT programme

ID	Mother Age	Mother Employment	Partner Employment	Autistic Child				Siblings (Ages)
				Gender	Age	Age at Diagnosis	Age when start PACT	
P01	39	PT job	Carer	M	6	3	5	Sister (22)
P02	38	FT job	FT job	M	5	3	4	Brother (13)
P03	47	Stay at home	FT job	M	11	3	10	Brother (9)
P04	41	Stay at home	FT job	M	8	3	7	Brother (21), Sister (20)
P05	33	Stay at home	FT job	F	4	2	3	Sister (14), Sister (13), Brother (12), Brother (9), Brother (8), Sister (6)
P06	43	PT job	FT job	M	11	3	6	Sister (9)

Table 7. Profiles of mothers of autistic children and their families – ages are in years

As for the therapists, three were from Manchester and two from Newcastle, and all were qualified as advanced speech and language therapists. The working experience of the therapists ranged from nine to seventeen years, and their experience with the PACT programme ranged from ten months to four years. All of the therapists were working full-time in the PACT therapy programme, except one therapist who was working part-time for PACT, two days per week.

6.3.3 *Design Process, Data Collection and Analysis*

The data collection approach involved a series of workshops with a variety of activities. A triangulation approach was applied in the ePACT case study; data were collected for sensemaking from various sources (therapists and mothers) and methods (workshop interview and design activities) (Yardley 2000). ePACT study was conducted in three main phases, as depicted in Figure 21. Each phase included a set of exploratory or design workshops. Each phase's results informed the design artefact of the following phase and helped to identify concepts and new directions to be explored in the next workshop. The first phase focused on understanding the current experiences with the PACT programme, along with the current and potential uses of technology. The second phase was aimed at exploring the design options and

establishing an agreement on key features for the self-coaching technology; these would be the basis for the preliminary design. The last phase was designed to critically reflect on the proposed design mock-ups. The second and third phases are covered in Chapter 7. Each workshop session was audio recorded, transcribed, and anonymised. The ePACT study led to the collection of 16 hours of audio recordings from the workshops, along with the written notes from the workshops' activities.

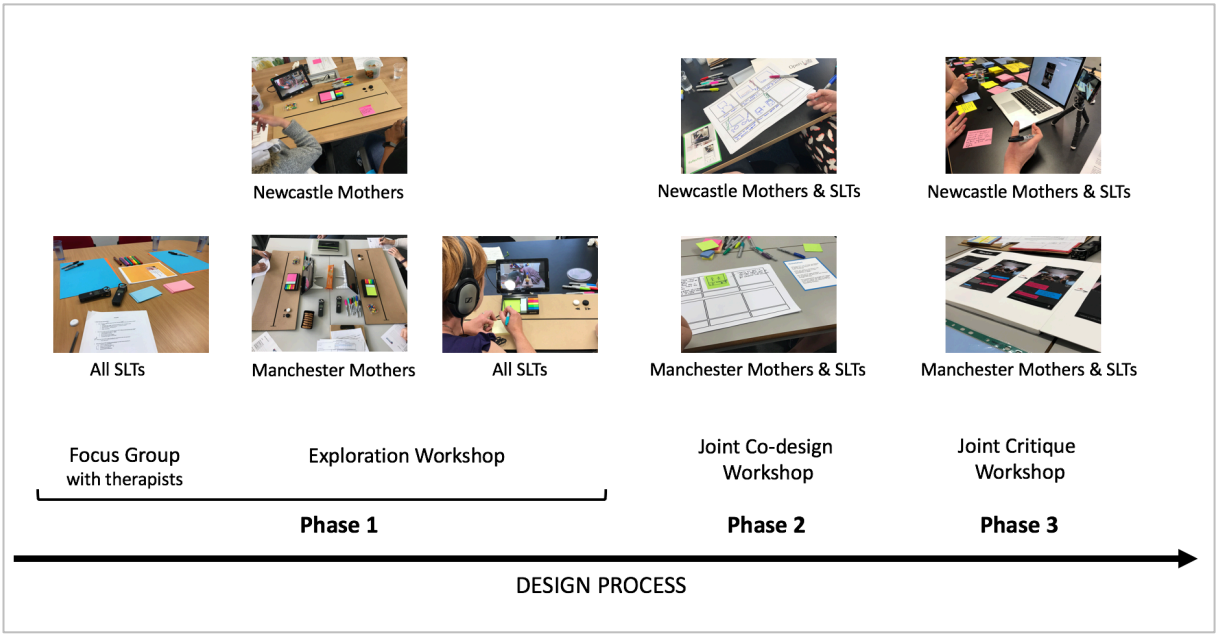


Figure 21. ePACT design process

Data were analysed using thematic approach (Braun & Clarke 2006). Inductive thematic coding was conducted on the resulting transcripts and the transcripts were examined line by line to allow open and low-level codes to emerge without any underlying theory. Initial codes were then compared and combined when overlapping discussion was identified between therapists, mothers, and activities notes from the different sessions. Codes were clustered together into recurrent and high-level themes, and then the themes described by the quoted data. Themes were then incorporated according to categories.

6.4 Phase 1: Study Design

As mentioned in the previous section, the first contextual phase of ePACT study was aimed at understanding the participants' experiences with the PACT programme, along with the current and potential uses of technology. In order to realise these experiences, the contextual

phase started with one focus group with the four therapists, followed by two workshops with the mothers in each of the research sites (one with the mothers from Newcastle and one with the mothers from Manchester), and another workshop with the four therapists. In this stage, the mothers and therapists were separated in the sessions to expose their alternative perspectives on the PACT programme without having any professional influence on the discussions (Muller & Druin 2012). Each of the focus group and workshops sessions lasted for two hours.

Focus Group

The focus group was conducted as the initial step with the group of therapists. It sought to understand the PACT therapy process in terms of the reality of practice at the different stages, solicit therapists' previous experience of supporting parent-delivered therapy, and explore the potential use of technology to support PACT therapy for self-reflection.

The first half of the session focused on investigating the real practices in the PACT programme. The therapists were asked about the programme's structure, including stages and strategies; the programme's impact and the parents' commitment; the feedback session, including video capture and reflection; the coaching techniques used; the current communication methods with the parents; and any challenges faced during the programme. In the second half of the session, the team envisioned and brainstormed on how technology can promote self-reflection practices. Initially the therapists were provided with blank cards in order to list the essential values and practices of the PACT protocol that were important to maintain in any self-coaching technology designed for PACT. The therapists were separated into two groups of two; they used blue cards to list the most important concepts/values and pink cards for the least important. A discussion was held at the end of the activity to reflect on the principles written down; it then moved on to thinking about the reality of achieving these principles in a self-coaching technology, with or without the therapists' support. Thus, the teams again used blue A3 cards to brainstorm the pros and cons of a technology not facilitated by therapists, and orange A3 cards for a technology facilitated by therapists (see Figure 22).

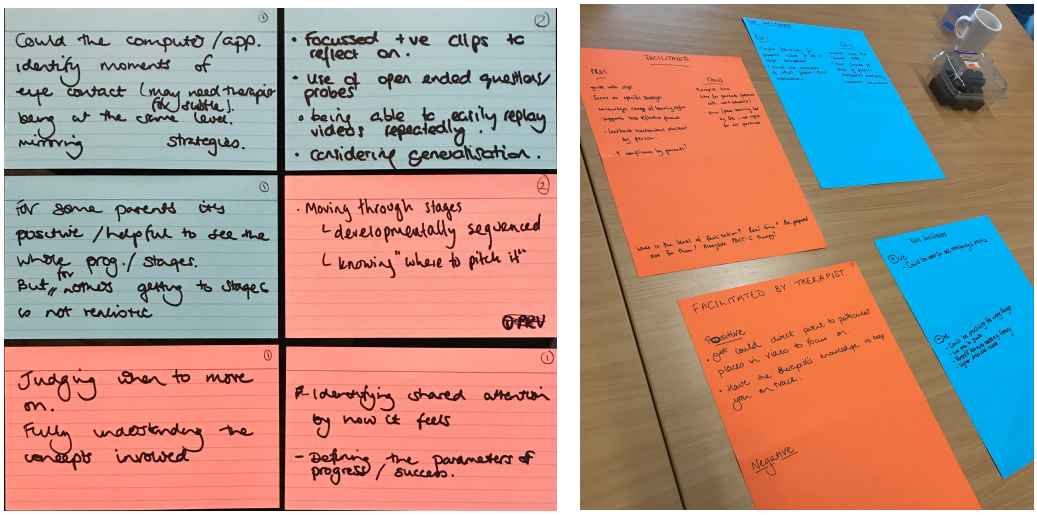


Figure 22. Brainstorming cards resulting from the focus group

Exploratory Workshops with the Mothers

We conducted two workshops with the mothers; one with the two mothers in Newcastle and one with the four mothers in Manchester. The workshops were designed to gain an understanding of the therapy delivery strategies during the PACT home visits from the mothers' perspective, and to explore existing use of digital technology and any potential challenges (e.g. convenience, privacy) of the use of technology to support PACT therapy. In addition to exploring the PACT therapy and its impact from their perspective, the mothers were specifically asked about their preparation for the visits or remote sessions, the practicality of capturing video at home, their personal learning styles, their management techniques for home practices and other responsibilities, and the involvement of family members.

In order to explore the potentials of self-coaching technology and understand the mothers' abilities with video feedback and reflection, a role-playing activity was designed using sample videos and annotation boards. The videos were collected prior to the workshop with the mothers' consent. The videos showed the mother and the child along with the interaction context from their natural environments and used in the design workshop for the video annotation activity. To avoid the sensitivity of discussions of personal mother-child interaction with the other participants, none of the mothers reviewed their own videos in the workshop. The annotation boards were designed to mimic the experience of selecting the good interaction moments and adding reflective comments (see Figure 23).

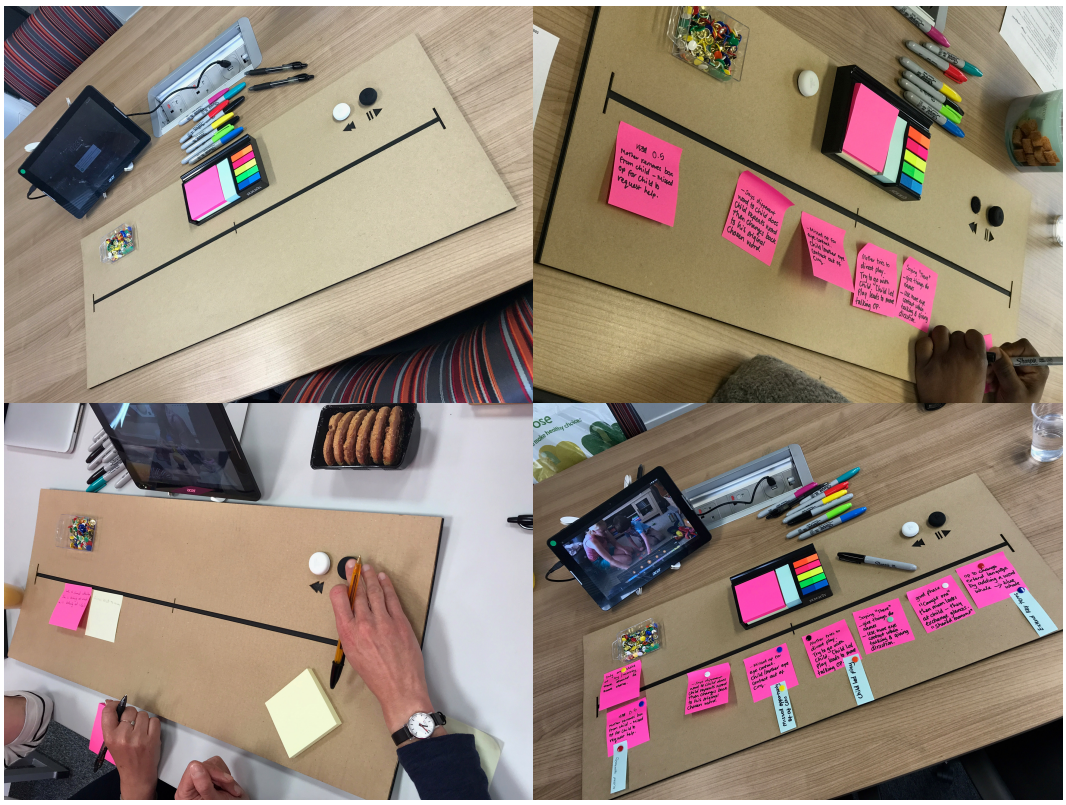


Figure 23. Video annotation boards in the mothers' workshops

The videos were played through tablets, and two Bluetooth buttons were configured to control the videos: one to *Play/Pause* and one to *Seek Backwards*. The boards had engraved versions of the video timeline bar and the two control buttons were attached to them. Each group of two mothers had their own boards and tablets. The mothers then reviewed the videos and added their comments and any other relevant annotations (e.g. strategy name or stage) chronologically to the boards using post-it notes. The act of self-reflection and feedback on video elements facilitated the subsequent discussions around the potentials of technology. The mothers were asked to discuss their experience with the video annotation exercise, the type of comments and annotations written, the expected level of support needed from the therapists, and how to make the self-coaching practices more convenient for the mothers to use at home.

Exploratory Workshop with the Therapists

A similar exploratory workshop was conducted with the four therapists from Manchester and Newcastle. However, the focus of this was to extend the initial discussions held in the focus group and ask the therapists to differentiate PACT from the PACT-G programme, and to discuss the suitability of videos captured by the mothers for reflective feedback and the practicality of remote sessions held through Skype. The therapists also performed the video

annotation activity in groups of two: one group reviewed a video similar to that used in the Newcastle workshop with mothers, and the other group reviewed the video used in the Manchester workshop with mothers. At the end of the annotation practice, the mothers' annotation boards where presented to the therapists, in order to compare them with their own annotations and assess the mothers' abilities to identify good moments without any professional involvement. Figure 24 shows the therapists' annotation and review activity. The activity scaffolded the discussions around the reality of video feedback through technology, the mothers' ability to self-reflect on video elements, the mothers' comprehension of PACT principles, and the expected level of support needed from the professional side.

Figure 24. Video annotation boards in the therapists' workshops – including review activity

The discussions transcripts that resulted from the focus group and the three workshops provided a comprehensive contextual understanding of the existing experiences with PACT therapy and the challenges surrounding the parents' coaching, as well as the ability to have an independent self-coaching platform. The outcomes were used to develop design activities and material for the next co-design phase, and to scaffold discussion on the design of the annotation and recording techniques.

6.5 Phase 1: Contextual Findings

The contextual phase exploration enriched our understanding of the PACT therapy context as well as the associated values and challenges of indirect therapy programme and the

practicality of self-coaching technology. In this section, we report the main themes of each of these areas; which reflect mothers' and therapists' perspectives.

6.5.1 *PACT Values and Practices*

Naturalistic Principles: Do More, Do Less, Try This

The mothers (n = 6) perceived that the introduced strategies and practices were not a massive shift, but were naturalistic, based on their current communication practices and focused on reconnecting them with their existing skills and understanding the parent-child interactions. The mothers also noted that they did not feel pressured but found the principles easy to embed in their everyday life. P06 remarked: *"I learned about the PACT principles, it seemed to be so naturalistic, and based on how I was communicating with my [child] anyway, except that I learned this really important theory behind why I was communicating the way I was, and how it was, and how I could improve."* This also included giving the parents further insight around the child's feelings in order to communicate better, as P02 commented: "*They might be able to explain that he is feeling anxiety when this and that happens. There are things that they can suggest – give you a little bit of insight into what they are feeling at that particular time and then I can adjust how I'm reacting to the situation to make it a bit more positive."*

The PACT strategies were defined by the mothers as focused on improving the parent's behaviours and child's communication skills through play therapy. As P02 expressed, *"If you fall into a pattern of behaviour and then not see any difference, then the therapist could point out what it is, because often it is us, as the parent or the other person, that is not communicating effectively."* The mothers (n = 6) described these principles as small changes with big impacts, such as 1) noticing spontaneous communication signs like the child's eye contact and then trying to repeat and expand these moments, 2) helping to improve the child's concentration on play for a longer duration by choosing one toy that draws their attention and removing others to avoid anxiety, and 3) expanding the interaction by hiding the toys in a bag to encourage the child to ask for the bag and then for the toys. Additionally, the mothers (n = 5) believe that they know their children best (i.e. their moods and preferences) and that the therapists try to assist them to find solutions; however, the mothers decide how to adopt these solutions in their daily routines.

The therapists (n = 4) confirmed the mothers' definition and expressed how these principles are more focused on the parent's performance than on the child's performance; starting from low interaction levels, like creating joint attention to help them to tune into the child's level and valuing the small interaction moments. For instance, the therapists (n = 4) remarked that there was a tendency for the parents to be more directive in their interaction with their children: T03 said: *"I am thinking of one of my mums, she was saying every time she used to come into the room to play with the train set, the child would like to stand up and take her out, because the mum kept being like, 'No, you have built the track wrong.' So, we gave her, her role, and it was just handing the next bit of track to build and as soon as she took that kind of facilitating thing, not directing thing, it completely changed how they played together and the enjoyment that the child shows increases."* One of the known stereotypes in autism is that parents believe their children cannot do stuff, or else they question their own abilities to interact with their children: *"My biggest barrier, pretty much most of the parents I have seen, the first thing they have said when I have said, 'We will take a video of you playing,' is 'He does not play, he just goes on his tablet.' But I think, once we get into it, they are very quickly showing that they can play, it is almost like you say, that the mums have not known how to facilitate that."* [T02]

The therapists explained that the introduced strategies are suggested in the PACT manual like a toolbox of practices to do in order to achieve the stage goal and increase and encourage communication. However, the therapist's role is to individualise and select from these strategies since they might not work for all children; for example, mirroring or repeating the child's language would not be a good strategy for all children based on their condition and behaviour. Some mothers (n = 2) confirmed that the introduced strategies were sometimes suggested by the parent, but the therapist usually explains the term and the theory behind it. As P06 said: *"And she says, 'Well, yeah, that is a mirroring thing that you have done there,' and I was like, 'Oh, right, well, I did not realise that.' But then she noticed the things on the video, and then she would say, 'Right, try that a bit more, try this a bit more.'"* [P06] Additionally, due to the naturalistic occurrence of these strategies, the therapists usually use the same language that the parents use to describe them, to ensure the right conception without enforcing new terminologies. As T01 commented, *"Because we are trying to get people to set their targets, in their words. So, it is about their conception of things and as long as their conception is right, then it makes sense for them to use their words to describe it, because that is meaningful to them."*

Mixed Coaching and Teaching

The PACT sessions were described by the mothers (n = 3) as like joint detective work where they collaborate with the therapist to figure out what was going on in any of the parent-child interactions and what to try next. The therapists (n = 4) confirmed that part of the PACT ethos is to promote more reflective thinking with the parent and avoid being directive, as T02 explained: *"That would be really un-PACT, because we actually really try and avoid saying – 'I think you should do this.' It was finding that balance of coaching her through it and modelling it, without again changing that power balance and being the expert that comes in."* Additionally, agreement on the meaning of the strategies, and conscious understanding, were deemed important for the reflection process, as T01 said: *"Sometimes they do not mean what we mean by it, so you will have parents saying until they are blue in the face, 'I let my child lead,' while they are going, 'Do this, do that, do this.' So, actually, there has to be some consensus about what the strategy is before they can begin to see that they are doing it."*

However, the coaching technique is heavily based on the parent's learning style. The mothers (n = 6) expressed that they learn from verbal suggestions mixed with demonstrations when needed. The therapists (n = 4) confirmed that the parent's style in the coaching session is internalised but this is not a barrier, as T01 remarked: *"It does feel like PACT is much more set up for people who are naturally reflective and I do have some parents who are very kind of short and to the point and it is trickier with them… their inner framework is making them behave in those various ways. But they are also more than happy to take on board what you have said. So, it does not inhibit the process, it just feels like they are not perhaps exactly what the coaching kind of technique is aimed at. But they still seem to get something out of it."* [T01]

The parents' coaching and learning styles became clear as soon as the therapist started asking questions regarding the recorded interaction as the main technique for coaching. However, in the first sessions, the therapists (n = 2) realised that some parents perceived these probe questions as validation of their understanding, rather than as a technique to discuss the content and figure out solutions. The therapists (n = 4) explained that they start broadly with non-directive coaching questions and then adjust their technique based on the parent's personal learning style. However, one therapist expressed that the process of reflection does not matter as long as the parent establishes the needed conception. To explain existing interactions or introduce new strategies, the therapists (n = 4) act based on the parent's personal style, for

example verbal explanation for reflective parents, modelling for directive parents, or drawing for visual learners. As T02 commented, *"I tend to do a lot of drawing stuff out for them. You might draw out this idea of triadic gaze and you would draw them the triangle between the toy and parent and the child to show them."*

No Linear Progression

Although the PACT protocol consists of several stages, there is the flexibility to revisit strategies from any earlier stages when needed. As the therapists (n = 4) expressed, there is no linear progression through the main stages, as sometimes the therapists realise that the mothers did not consciously understand the strategies in earlier stages, or that they are falling into their old patterns of behaviours rather than the new strategies being properly embedded. Thus, the therapist commonly revisits strategies in the earlier stages when needed, even if the parents have progressed to a higher stage. For example, T04 remarked: *"Keeping the previous strategies is really important because as you move through the stages, lots of my parents, we get to stage 3 and all of a sudden, you have to think, 'Hang on a minute. No, you have completely forgotten what we have talked about at stage 1, go back and explain.'"*

The progression between stages is based on several factors. First, the parent's understanding of the related strategies, as T02 mentioned: *"The criteria have got a bit of flexibility for a bit of professional judgements, so for some parents, the child might have met stage 1 criteria, but I do not think the parent is conscious enough of the strategies, so I might give them another session at that stage."* Second, the parents' cumulative performance through the coaching process, as T03 explained: *"You either have parents who once they have hit the end of stage 3 the rest seems to flow quite smoothly, or you have the ones who are stuck at stage 1, 2, and 3 for a long time because they are not getting it."* Finally, it is also based on the child's condition as the higher stages are more concretely focused on language and some of the children are non-verbal. However, the therapists (n = 4) confirmed that the mothers are not aware of the overall framework of stages and progression; instead they explain the targets of each strategy and what they are working on. Thus, the mothers (n = 5) have a sense when they are moving and what is the current focus is, but without adding stress if there is slow or no progress.

Facilitating Identification of Moments

Identifying good moments of interaction between the mother and the child in a recorded video is central for the reflective discussion to build and expand on those key moments. The mothers (n = 6) believed in the therapists' abilities to identify these spontaneous actions that they are not normally focused on (such as eye contact) and finding ways for the child to communicate more in a situation. Some of the mothers (n = 2) perceived the therapists as trained experts who were able to identify behaviours invisible to the parents, as P01 remarked: *"Obviously with her being there and being able to pick those bits out and show me, I am more aware now of those type of things. But obviously they are trained to spot those things, are not they? So sometimes for us, as parents, it is less obvious."* [P01]

In the mothers' (n = 5) experience, the identification of moments is led by the therapist to point out what was wrong, what was right, and what to work on. With experience, the mothers start to realise the missing opportunities and visually see what is wrong. As P03 said: *"She tended to have certain parts of the video that she would flagged. She would start, probably, with a bit that she liked. She said, 'I really liked the way that [child] did this,' or, 'This was a lovely moment, when he looked at you.' And then, quite often, I would see where I had gone wrong, and say, 'Oh, yeah, I should not have done that,' because you know eventually, do not you? And you think, 'Oh, that was wrong.'"*

While the therapists (n = 4) explained that this identification process is focused on positive communication moments, as well as monitoring the parent's emotional responses to the videos, as T03 commented: *"Some moments where I think 'That is really good,' but they are kind of a bit uncomfortable about whatever has happened at that moment, because of what follows it or precedes it. So, partly it is kind of reading a parent, and going, The strategy is done well enough, and the parent will respond positively enough to that moment I have picked."*

The prop questions are used by the therapist as a way to indirectly point the parents to these moments, and sometimes the therapist takes more control over the selection of the moments. For example, T04 said: *"When I asked, 'What went well?' One mum was like, 'The bit with the shape-sorter, I thought that was really good.' But I had the exact time of the best moment in the shape-sorter, so I was like, 'The shape-sorter, let's go to 4m32s.' She was still saying, 'I want to talk about the shape-sorter bit,' but I was saying, 'Within the shape-sorter bit I*

want to talk about how you mirrored the sounds that you were using.'" Consequently, with more experience, the therapists (n = 2) noticed that the parents were getting better at this identification process.

Repetition, Generalisation and Monitoring

The main principles behind the PACT protocol and video sharing for Skype sessions are to encourage repetition of the practices learned and generalisation through embedding these practices in daily play routines. Some of the mothers (n = 4) noted that the therapist was always supporting them to repeat the practices by saying, *"Try that a bit more."* Other mothers (n = 3) noticed that the repetition helped them to adopt the strategies, as P05 said: *"With the first video that I did, I could see that I was not as good, but then, when she was leaving me strategies, and I was doing it at home repeatedly, it just became a normal routine."*

The therapists (n = 4) confirmed that the videos requested between sessions are to monitor the home practices and ensure correct understanding and generalisation. T02 noted: *"I think once parents have got the gist of PACT then their generalisation videos get much better. But if they have not quite got it by the third session when they do their first generalisation, sometimes I have had some really random bits of videos, that have not been quite what we expect."* One the therapists [T01] mentioned that making these recordings at home and not in the clinic should help the parent to think on how they can do it in their life. However, the therapists (n = 3) are looking for more naturalistic adaptation of the PACT practices, as T03 said: *"We are trying to get them to focus on generalisation. As they move through it, it gets less and less about setting up a play session and more and more about noticing you are playing in a PACT kind of way and so those moments, if they can get them on video, actually make really great generalisation videos because they are doing it naturally."*

6.5.2 *Unpacking PACT: Experiences and Challenges*

PACT Impact

At the beginning of the PACT programme, the therapists (n = 3) confirmed that there was a mismatch in expectations between what the parent wanted for their child to achieve in PACT and what the therapists were going to work on. Yet, a more realistic agreement was established when a clear understanding was developed by the parents throughout the

programme about the child's condition and the therapy protocol. As T02 commented, *"A lot my parents, you say, 'What do you want from PACT?' and they will say, 'I want my child to talk.' So, you have to kind of say, 'Okay that is your ultimate…' It is about explaining that framework behind it, I guess, that, 'You want up there, and we are starting here, and this is why.'"* From the mothers' perspective (n = 3), PACT is considered a form of speech therapy delivered in the child's early years to reduce the symptoms of autism or make communication easier for the child in the future. However, the mothers (n = 2) expressed that the NHS funding limits their access to the therapists for preschool children; thus, they appreciated having PACT as a more focused therapeutic programme.

The mothers confirmed that they had noticed various improvements in the children's communication skills. These included non-verbal children discovering new ways to communicate (n = 1), or starting to say a few words (n = 1); improvements in the verbal children's confidence as they started to speak with other people (n = 1); the children starting to initiate the play session and become more independent (n = 1); the children developing more language and more repetitions (n = 1); and increases in the children's concentration spans and attention from playing with single toys for a few seconds to 8 minutes (n = 2). The mothers
(n = 2) noted that the PACT therapy is for them as well; with the ongoing support, they found that their personal communication skills had improved (n = 3), it had become easier to communicate with their child (n = 2), they had developed a better awareness and knowledge of the autism condition and interaction strategies with an autistic child (n = 2), and had gained access to new play ideas (n = 1).

"I think it made things easier for me and my family as well because we have just got to understand a little bit more about how autism works and how it affects him; and how we can just sort of unlock him a little. So, when we started the programme, he had actually just started talking. He was saying, maybe, two to three words sentences. So, it was a good time for him and it was just building on that." [P02]

Due to the naturalistic nature of the PACT principles, built on the existing parent-child interaction, the mothers (n = 5) felt that they were practical, easy to use, and became part of their life without any massive change in their play routines. Additionally, the strategies' names were found to be clear and became part of their everyday vocabulary as they

repeatedly used them with the therapists (n = 3). P06 remarked that *"I feel now that I do PACT therapy, but I sort of do not, I just communicate with my child. It just happens to follow the PACT principle."* Moreover, the video capture helped to reveal the child's progress to the mothers (n = 5) since they were progressing without realising it due to the immersive daily interaction. As P04 said, *"It was also sharing the videos that he was doing at school with me, and also seeing the moments that he had there, and just how far he has come in that short space of time that we have been doing PACT."*

The therapists (n = 4) found that the PACT programme positively altered the mothers' skills, consequently affecting the child's communication. These improvements included giving the parents more practical ideas to work on (n = 4); realising their own experiences and improving their confidence to communicate their own knowledge to other professionals (n = 1); increasing the parent's confidence in risk taking, such as taking the child into public spaces (n = 1); improving the parent's awareness and understanding of their children and the interactions
(n = 3); and giving the parent more control over the parent-child relationship and the difficulties faced (n = 1). With the better understanding of the communication behaviours established by the mothers, the therapists (n = 3) found that the mothers started using some of their discarded old toys, since they realised how to use them with their children. Also, the children became familiar with the mothers' communication signals and tried to respond: *"And I think often thinking about the therapy and all the children, a lot of the time the feedback is, 'I understand the child better, I understand him'."* [T04]

Ongoing Support and Compliance

Although the mothers valued the impact of the PACT therapy, some of them (n = 3) noted that they started to be more committed in adopting the strategies when they realised the benefits of the more intensive therapy programme. As P03 remarked, *"I think the first time I did it, the programme was not so intense, I was not doing it as often, it was just playing with my son. So, really, I did not see as big a benefit as I did this time, where it was more intense – I did more of it, and I was quite committed to it. I was quite amazed, actually, in terms of [the child's] interaction."* All the mothers (n = 6) found themselves committed, as these practices are flexible enough to fit into any communication situation, such as during bath time, while reading, or while getting ready in the morning. As P04 said, *"It is just you playing with your child, so it is not even something that you think, 'Oh, I have got that task to do or that is*

something I have got to fit in,' because you want to engage with your child anyway, so it is just part of what you want to do every day. And it is fun, and they found it fun as well." However, having a continuous 30-minute play session daily is considered a long duration for an autistic child, so the mothers (n = 6) try to break it up throughout the day whenever the child is ready to communicate or play. The mothers (n = 3) noted that they usually start with a few minutes' play time, and then extend the duration as the child's attention span gets better.

The therapists (n = 4) also confirmed that they were getting good compliance from the mothers and they were not strict about half an hour's daily practice. Additionally, some of the therapists (n = 2) noted that some parents showed high compliance, while others were very explicit in communicating their forgetfulness or any limitation faced due to their other commitments or distraction from siblings. However, the therapists (n = 4) noted the importance of the parents' commitment for developing these practices into habits. Some of the techniques that the therapists were using to explore parent compliance included feedback questions, videos captured at home, or the live play session recorded during the session.

Furthermore, there was no direct communication between the therapists and the mothers between the sessions; except for the home programme received after each session by email, or calls to schedule appointments. The mothers (n = 6) confirmed that these programmes were not pressured and provided a clear plan on what they could do and how to do it. Thus, the mothers revisited these programme sheets to remember the strategies when needed, and some of them (n = 3) said that they put them on the fridge or organise them in a folder to ease access. As P03 commented, *"I just think sometimes you just fall into your old patterns and then you think, no, no, I must use the strategy and then it starts working and you just sort of remember to just keep using that sheet."* The mothers (n = 4) also noted that they kept doing these practices even after the programme period as it came naturally in the way they interacted, and they referred to the home programmes when needed. However, these practices files were protected by password or encryption, and the therapists had no way to confirm if the mothers' received or accessed them until the next session, as T03 remarked: *"Quite often I have not found that out until one of the first things you ask them at every session is, 'How have you got on with practice?' If they go, 'Oh I do not know because I could not open the thing,' and I am like, 'Well, remember you can always tell me next time.'"*

Nature of Video Guidance in PACT

The video reflection practice is the central activity to coach the parents in the PACT sessions. The mothers recognised various benefits of re-watching the recorded interactions. These included realising the wrong interactions (n = 1), correcting themselves even before the therapists said it (n = 1), helping them to compare video recordings and see progress in the parent-child communication (n = 2), helping them to overcome frustration by noticing the child's development (n = 1), appreciating their abilities to communicate with their children (n = 1), discovering the child communication signals that they missed in the real interaction (n = 3), and visually learning what to do in a situation (n = 1). The mothers realised the benefits of the video reflection practice: one of them confirmed that they continued randomly doing a similar practice even post-therapy. Additionally, the therapists (n = 2) added that the mothers celebrated their success by sharing the good moments that were recorded at home, as T03 noted: *"I think sometimes, they just want to share a moment. So, we would ask for those videos, and if it has been a good moment, she just wanted to be like 'Look, we did a thing.'"* Yet, from the therapists' point of view, the main benefit of the reflection practice is that it helps the mothers to slow down and realise the small communication signals from their children, and tunes them in; subsequently, this facilitates discussion strategies to expand these interaction moments.

"Sometimes the child is responding but in a really brief way, that you are getting like a tiny moment where the child glances at the parent. So, you have got the video, where you can take them through that moment, and get them to actually physically see how small that response can be and sometimes that is a really good way to start getting them tuning in." [T01]

Furthermore, the interaction context and the child's personal behaviour sometimes affects how to perceive the child's communication, and the therapists (n = 3) confirmed that the mothers are better at explaining the communication signals due to their personal experience with their children. For example, T04 said: *"I really thought the boy had shifted his attention and she had not followed him and I was asking her to watch that moment and I said, 'What do you think is happening in that moment?' and she said, 'I know exactly what is happening at that moment, he is having a poo.' [Laugher] And I was like, well, that was my whole session planned, gone."*

Additionally, while it was challenging to have low-quality video recorded (i.e. not properly showing the context), the therapists found that useful to promote the mother's reflective skills as they had to explain further the interaction or/and the context. Nevertheless, the therapists (n = 3) noted that this reflection practice was an emotional experience for some parents to deal with, due to the acceptance of their child's condition, their anxiety, and their disbelief in their own abilities; or because they were very focused on the negative communication moments. As T01 remarked, *"Sometimes you do just have discussions where they do end up crying… So sometimes you have to have that discussion and acknowledge that it is difficult and painful. Then, move on to 'There are other small things here that we can build on.'"* The therapists also had faced some challenges during the reflection process. These included parents' low engagement and lack of focus during the session, which transformed as soon as they saw the value (n = 1); slow perception of the overall programme process and being less reflective

(n = 1); low literacy, meaning that parents cannot work with text but are more visual (n = 2); and the child and/or siblings' distractions during the parent-therapist discussion.

Remote Coaching Experiences

The mothers (n = 6) found it easy to use the Skype technology for the therapy sessions, even if they were not familiar with it. Compared to the actual visits, the short duration of these remote sessions (30–40 minutes) made them manageable to arrange by the mothers (n = 2). Additionally, these remote sessions were considered as maintenance sessions by some therapists (n = 2), since they found it hard to remotely assess the skills developed by the parents and progressing them to the next stages required more evidence. Meanwhile, the mothers

(n = 2) perceived these remote sessions as follow-up sessions between the main visits where they could ask further questions about the practices with no distractions (e.g. by planning the session to be around school time). The therapists (n = 2) also confirmed that they got better attention from the parent as the child was not around. Although all therapists (n = 4) had more time to think and plan for the sessions beforehand, the remote session delivery was considered new to their national practices and they felt they lost control over the context surrounding the mother: *"It feels like a bit of luxury compared to the other sessions when you have to do it there and then, so it is quite nice to have a little bit of time."* [T01]

However, the therapists and the mothers experienced some practical challenges with the remote therapy sessions. With the video sharing, big video files had to be trimmed before sharing (n = 1), or it consumed time to send them and troubleshoot any file sharing issues (n = 1). Also, synchronous video watching was one of the main issues mentioned by the therapists (n = 3) as they were not watching the video quite closely with the parents on the same screen to ensure that the right moment was discussed. Due to the fact that some mothers were watching the videos and Skyping from the same smartphone, the therapists (n = 4) had some interruptions due to the mothers' need to switch between the applications and receive phone calls or text messages. As a solution, some of the therapists (n = 2) asked the mothers to watch specific moments offline before the session started or call them again when they had finished watching. One therapist had a different experience: *"I have done it where I have had the video on my phone, Skyping on my computer, and I will turn my phone around so instead of seeing me, they can see the video and then watch it together."* [T04] Finally, the therapists (n = 2) noted that they generally had difficulties in teaching the parents through Skype due to connection delays, pauses, overlapping conversations, and the lost ability to draw for the visual learners.

Self-Collected Moments

The mothers expressed that capturing a playful interaction with some of the children in a new environment made the children feel overwhelmed, stressed, anxious, and distracted; it also felt invasive to their privacy due to the many people around. Similarly, the mothers (n = 5) confirmed that they had been more self-conscious about their look and sound at the beginning of the therapy experience, but then they became more focused on the children and forgot about themselves. The therapists (n = 4) confirmed this and added that sometimes the mothers were anxious about some of the recorded moments, as T03 explained: *"Sometimes the child does something that the mum does not want on video. I think the mums are sometimes quite embarrassed about that situation and how they manage that, and that can feel quite uncomfortable."*

Whenever the children were in a good mood and very interactive, the mothers got an opportunity to practise and capture their interaction. Yet the mothers (n = 3) expressed that it was always easier for them if someone else made the recording while they were just focused on the child. Sometimes the child is interested in technology; thus, the mothers (n = 3) had to subtly capture the moments without the phone being noticed. The therapists mentioned that

they had to accept various video qualities, such as many children in the scene (n = 1), recordings with voices only (n = 1), selfie recordings or showing the parent's view only (n = 2), or in which the good interaction moment was not captured (n = 2). One of the therapists expressed how low-quality video is difficult to use with the parents who are not naturally very reflective, as they cannot get further verbal details. Three mothers and one therapist also found that setting up the phone while interacting interrupted the play session and broke the interaction, as P06 said, *"But it is the amount of times that I have just thought, 'My phone's over there. If only I could just go and grab it.' But I know if I get up and grab it, it will be gone."*

Shifting Roles: Parent as Therapist

Beyond the therapy sessions, the mothers start acting as experts to coach and teach their families and other caregivers. Three mothers expressed that they share the strategies with family in order to ensure generalisation and adoption outside the home and with other people, and access support for the child's daily care routines. As P05 commented, *"I used to get my older siblings, one of whom is actually as tall as myself, to do the same thing as well. So, I do not want to be doing it all the time myself, if you know what I mean. I want all of my family to be doing those strategies with her."*

The mothers used to share their experiences through verbal explanation of the strategies, sharing the home programme, modelling the mother-child interaction, or sharing video examples. Moreover, a mother found it useful to jointly reflect with her partner on the recorded interactions as a way of sharing experiences, as the partner did not attend the therapy session. With their established confidence, the mothers (n = 3) realised their own experience, as they were able to observe other people interacting with their child and advise accordingly. Some mothers (n = 2) noticed that other siblings developed their knowledge to communicate with an autistic child and started to correct other people, as P06 noted: "*My nine-year-old daughter when she hears visitors coming, who obviously do not know anything about this, and if they start asking, 'Oh, hi, [child name], what are you doing?' she is like, 'Urgh' because he will never respond to that, because it is like a demand. So, I think it just starts to pervade the space, about how to communicate."*

Trust and Sensitivity of Support

Generally, the mothers showed their trust and reliance on the therapists' expertise, compared to other support channels such as peer families or support groups. As P01 commented about the lack of post-therapy support: *"You feel you have reached a level, a perfect level, well, a lovely level, but then you are like, what do I do from here? Because you do not have anyone coming around and pointing out things."* Throughout the therapy sessions, a stronger and trustful relationship had been established between the mother and the therapist, as P02 expressed: *"It is important to build up that relationship with the therapist because you are sort of laying yourself bare. She gets to see your highs and your lows, and not a lot of people get to see that."* Meanwhile, the therapists (n = 2) said that this relationship helped them to better understand the mothers' behaviours and habits. For the mothers (n = 2), the speech therapists sometimes play multiple roles, as they seek several types of advice from them as if they were occupational therapists or educational psychologists. The mothers (n = 2) also felt that they were sharing their concerns with someone who understood their situation and was able to reassure them and acknowledge the difficulties they were facing. Some of the therapy sessions were noted by the therapists (n = 2) to be less focused on developing skills, but more sympathetic to relieve negative feelings or challenges facing the mothers and point them to the appropriate service if possible. Especially in rural areas, the therapists (n = 1) noticed the mothers' need to chat as they were more isolated and had not seen other professionals, as T03 remarked: *"Sometimes, it is worth spending ten minutes going, 'What is going on with you? You are being quite harsh on yourself today, shall we talk about that for a bit?' Because once you have got that out of the way, then you would get twenty minutes of good discussion. Whereas if you let that colour the whole thing, you would get poor discussion."*

Furthermore, some mothers (n = 3) expressed how they would discuss their experiences and concerns with professionals rather than peer families, as this helped them to stay positive and gain more professional support. For instance, P06 commented, *"I get more support from professionals than I do talking to peers, because it is sort of more positive than a whinge-fest. Although PACT has been brilliant for my son, it has also been great for me, because I have felt that I have had an ongoing support from someone that I really respect and trust."* Conversely, other mothers discussed how they had created a network for themselves to access peer support, either by joining online groups (n = 3) or establishing friendships with families who had children with autism (n = 1). The main challenge for the peer support, as expressed by the mothers (n = 4), is the associated judgemental feelings, and that every child on the

autism spectrum is different, which makes their experiences truly unique, and the need for personalised strategies that work for specific mother-child interactions. However, two mothers discussed their personal experience of sharing general advice with other peer families about the available health and therapy services. The therapists (n = 3) assumed that peer support would have a positive impact as it allowed the parent to discuss their child's condition with someone who had a similar experience, as T03 commented: *"Sometimes having someone else who has done it, rather than me as a childless therapist, going, 'Just hand over control, off you go,' and I think that would have helped."* In fact, some therapists (n = 2) experienced some of the mothers requesting sample videos from other peers, which they were not able to give them due to the restrictive policies.

6.5.3 *Feasibility of Self-Coaching Technology*

Potentials of the Therapist Role

There have been some debates around the need for therapist support in a personal coaching technology that can used by parents. The discussions were mainly focused on the parents' self-coaching abilities and the needed level of professional support. A technology without therapist facilitation and guidance was argued to be challenged by misinterpretation of strategies; erroneous adaptation; parents' learning needs and their literacy levels; and the loss of the human side which would affect the parents' motivation and commitment. Nevertheless, these technologies are more flexible for parents to use for self-monitoring and reflection practices when it is convenient for them. The therapists (n = 3) were doubtful about the parents' ability to self-learn the concepts and strategies when introduced through technology, either through textual explanations or sample videos. As T03 remarked: *"Many parents will hear you say, 'Letting the child lead is important,' and they will say, 'I am letting the child lead,' but they are not at all. They do not really understand what that means... They are using the same words, but they do not have the same idea at all."*

A suggested technique to introduce new strategies is the use of sample videos from other parent-child interactions to show parents how to implement a strategy and provide them with new ideas for play. However, this is challenged by the parents' unwillingness to share their personal experiences with peers, since every child's condition is different, and the strategies are individualised. Therefore, the therapist's role remains important to observe and understand the needs and abilities of the family to introduce suitable strategies and suggest

ways for adaptation. As T02 remarked, *"I think parents would find it really hard if their child is non-verbal and you show them a video of a verbal child. In fact, it is worse. It could be the other way around as well, that if you show them videos of a non-verbal child, they are going to go, 'Well, my child can talk.'"* Although some of the mothers (n = 2) believed that there were limited funds for these therapy services and the parents' community should support and coach each other, other mothers (n = 4) were uncomfortable with the idea of sharing examples from their practices with other parents. Instead, some mothers (n = 3) suggested using examples from their child experience to learn strategies, as P04 commented: *"If the therapist has got some input when you can then see examples of your child in the moment when they have done that strategy, so actually, then you compare [them] against your own, rather than anyone else?"*

On the other hand, the therapists (n = 4) believed that a technology with professional support would consume the therapist's time and be pressured with the parent's work schedule. However, they argued that this support could diminish the previous challenges by encouraging a range of learning styles and supporting less reflective parents, increase the parents' compliance, help the parent to focus on specific strategies one at a time, direct the parent to particular places in videos to focus on when needed, and provide a feedback mechanism to keep the parents on the right track. The therapists (n = 4) agreed that more professional facilitation is a must in the earlier PACT stages and with less reflective parents, and this can be reduced as the parents manage to generalise or while they are in a maintenance stage. For example, T03 commented: "*You would need some level of therapist facilitation in there. It almost feels like the more you get into generalisation, maintenance, and those kinds of things the more it would come into its own. But when you start, the facilitation is going to need to be much, much higher to make sure that you do not go off down some completely wrong track."* Parents' self-coaching abilities are affected by the level of their comprehension in adapting the therapy principles, as T04 remarked, *"You either have parents who once they have hit the end of stage three the rest seems to flow quite smoothly, or you have the ones who are stuck at stage one, two, and three for a long time because they are not getting it."*

The mothers (n = 5) also confirmed the importance of the therapist's role in the coaching process and were keen to design a self-reflective tool to develop a model of therapy where the parent can remotely get on a bit of advice and progress rather than waiting for the therapist's

visit. Some mothers (n = 3) argued that the discursive element is a key part of the PACT programme as they rely on the joint explanations and the rational analysis of the parent-child interactions. Thus, they felt the technology could be used in conjunction with a therapy programme in order to improve the parents' skills; but could not stand alone. From the mothers' (n = 4) experiences, they found that they would struggle to adopt these strategies if they had not done some home therapy before; thus, they found the technology to be more useful to progress with the learned strategies and access feedback. For example, P04 commented: *"This was going to be still with support from a therapist, but they are not having to come to the house… And, obviously, you would have to do a course first with therapy, because your child needs that, and you need that, and then you could use this app to progress, with a therapist just giving comments. And, obviously, they might not be able to watch the whole thing, but you could then send a short version of it and say, 'What do you think?' So, you need feedback."*

Amendments and Expectations

A self-reflective technology was suggested to be useful to maintain the parents' skills, promote their reflective-thinking abilities, and build more personal experiences that mimic the video feedback practice held as part of the PACT sessions. The therapists (n = 4) expressed that ePACT can be used for the parent to: self-practice, progress with their skills, remember the strategies, and easily communicate their concerns to the therapists. The importance of the parent's familiarity with the PACT protocol before using the system was reinforced, as T04 said: *"You would need to get a certain way down the road before you start self-analysing, because for most parents, although it might chime with their mindset, it is a very different way of thinking."* The therapists (n = 3) also suggested that the tool would be useful for the professionals as a backup tool in between their sessions to monitor the parents' compliance and provide help accordingly, as well as in the maintenance phase where the parents receive fewer sessions. Some of the therapists (n = 3) thought this particularly useful to access concrete visual evidence of home practices rather than verbal explanation from the mothers. The therapists imagined that remote coaching technology would help them to verify the parents' comprehension of the PACT principles, such as focusing on positive moments of the interaction, and the correct understanding and adaptation of the strategies. Likewise, the therapists suggested using the self-coaching technology as a tool to coach the parent during their visits; thus, the parents could directly access the session notes with visual examples, reducing the pressure on the therapists to write the home programmes afterward. This would

be particularly useful to reduce the visit time, if the parent had used the tool to prepare for the session by capturing and watching the video earlier. Moreover, a potential change in the PACT protocol, suggested by two therapists, was to replace the Skype session with remote commination with ePACT. As T02 commented:

"I wonder if this, almost, replaces the every-other Skype sessions? So, have an opportunity to send reflection videos that will be reviewed offline in between sessions. But if there was a really, 'We do not know what is going on here,' or really wanting to drill into an issue, you could then be, like, 'You have raised an excellent point. This is complicated. Let's arrange a time where we can have a chat about it.' So, you can mix the offline and the online."

Additionally, the mothers (n = 5) also emphasised the benefit of having a simple tool to easily apply the video reflection practices; especially for self-practices without direct therapy support. As P06 explained a simple reflection process to be: *"What I do when I sit down and watch the video, and I have got a pen and paper, and so I will pause it on the computer, I will jot down the time code, and I will just describe what has happened, and comment on what was good about it or what was awful about it. So that is my process, so it would be something on an app, where I could watch, and I could pause, and then flag something, and then a comment. That would be what I would want!"* The mothers also confirmed the importance of having an accessible tool on tablets or smartphones, except for one of the mothers who found smart TV to be popular for watching videos.

Furthermore, the therapists (n = 3) revealed that the good thing about PACT is conversation and immediacy of feedback. From the therapists' perspective, to replicate the video feedback experience, the central elements that the technology should support are identifying positive moments (n = 2), the therapist's ability to remotely point out the moments remotely (n = 2), and to establish a moment-related reflection (n = 3). In order to support the moments' reflection, the therapists used open-ended questions as probes during PACT session. Thus, automated probes based on specific interactions was one of the therapists' concerns (n = 2). Moreover, the mothers expected the therapists' feedback to consist of guidance on selection of moments, reassurance about home practices, correcting the parents' behaviours, advice on new strategies, explaining existing interactions, and emotional support. The therapists added that they might provide less directive feedback to compare moments and show progress, credit the mothers' achievements, and support repetition and generalisation. Additionally, the

mothers expressed the possibility of using the system to receive feedback from other professional carers such as occupational therapists or educational psychologists. The mothers (n = 4) confirmed their interest in sharing their personal video recordings with their therapists; without having any privacy concerns as they used to do this with Skype sessions and had established a trustful relationship. However, the mothers expressed their need for assurance that the therapists would be committed to help. Furthermore, the mothers (n = 3) stated that coaching solution would be useful for the other family members and caregivers as well, since the mothers would be able share videos with comments to teach and update them. As P04 commented, *"You would send an annotated video to a family member, so they could get a sense of how you are doing it."*

The Challenge of Selecting Moments

The therapists believed that the identification of moments should be initiated by the parents to avoid restricting their reflective thinking or increasing their reliance on the professional's expertise. Moreover, the therapists (n = 2) questioned the abilities of the technology to facilitate the identification of moments based on concrete aspects, such as eye contact, positioning, shared attention, mirroring, and so on. However, the therapists (n = 3) realised that some of these interactions were identified by the therapists based on their experience rather than using any visual or audio signs. For example, T02 commented: *"Talking about the shared attention, it sounds really woolly, but you just know it when you see it. They can look like they are looking at the same thing but just by being there you know that they are not. It is quite subtle for some children."*

During the live experience of video annotation using sample videos, the mothers (n = 4) stated that they were able to identify many moments within the interaction easily. However, some mothers (n = 3) said that they were challenged in identifying these moments because of the camera position and child movements, and because they were not part of the interaction context. For instance, P05 commented: *"It was hard to tell whether he gave eye contact, which he did, she sort of looked at him, and you could sort of tell he did. But you could not see his face. We had a bit of trouble with that on our video, because they are just moving around all the time. So maybe that is the thing that is difficult here, because it is not your video."*

As we observed the video annotation activity, the mothers were really quick in locating many moments, while the therapists were more careful. In the first video, the mothers identified seven moments, while the therapists identified five moments; in the second video, the first group of the mothers identified seven moments, and the second group identified six moments, as did the therapists. We reviewed the mothers' selections with the therapists to explore the ability of the experienced mothers in this identification process. Some of the therapists (n = 2) expressed their interest in observing the mothers' selection as it revealed the mothers' perception, and T01 remarked that *"It is interesting, because usually we do not allow them to go alone down the route with why they think it is good, really reveals what their inner framework is for what they are doing."*

Generally, the therapists noticed that there were some mismatches between the mothers' selections and the therapists' selections, which is normal even during visit discussions. But the therapists would not have identified some of the selected moments as good moments. Although "negative" is not a PACT word to be used by therapists, the mothers used it in this activity as a moment tag. The therapists observed that some boards were more focused on the negative interaction moments or missed opportunities, rather than focusing on the good opportunities to improve. Among all of the mothers' boards, there were nine negative moments out of the twenty moments selected by the mothers. Some of the therapists (n = 2) noticed how a mother repeated her old habits to be more critical in her reflection. For example, T03 said: *"It is her natural style of reflecting. She would naturally go into, 'I did not do this then and I did not do this then,' but that is not PACT. So, in the sessions you steer them away from that and you go, 'OK, but what went well? What did you like? What is good here?' But when she has done it without any influence of that she has gone back to "This did not happen.'"* The therapists also agreed with some of the mothers' selections of good moments. The remaining eleven moments selected by the mothers were identified to be less critical and more focused on the good communication opportunities. The therapists were pleased to figure out that some mothers were able to be more positive in their reflections.

However, when we reviewed the mothers' annotation boards, we noticed that they were rarely using any formal strategy name; e.g. the strategies were called missed opportunity, child-led play, interaction, shared attention, and modelling. Some mothers (n = 2) explained that it was challenging to tag a video without having specific targets or strategies to focus on. The therapists also noticed some incorrect strategies were selected or that the parents

misinterpreted the strategy's meaning. For example, T01 commented: *"Mum sitting holding her hand out which we obviously feel is like a demand, but they think it is interaction. And yes, she is at his level, but she is actually really close. But you can completely see why they say those things, because the child then gave it!"*

Additionally, the mothers (n = 2) stated that their comments were based on the experience they had gained from the PACT trail rather than being generic comments. We observed that many of the mothers' comments were focused on describing the interaction, either as a missed interaction opportunity or a successful communication. However, the mothers (n = 4) felt that their comments were self-explanatory and explicitly identified goals, as P01 commented: *"In the comments here you are saying, 'mother removes box; missed opportunity for child to request help'. So that is what you need to build on."*

Although the mothers were not commenting on their own videos, they found it easy to comment on other people's interactions because they had either had a child with a similar condition or behaviour (n = 2) or it was one of the basic communication strategies that fitted all circumstances (n = 3). Moreover, the therapists' comments were more focused on identifying a mother or a child action in order for them to establish a deep reflective discussion with the mother. The therapists (n = 4) explained that their comments were basically like conversation prompts and less descriptive, as T04 remarked: *"They are the sort of things that we would write down when we were watching back the video with the parent and think, 'we will come back to that!' So, for this, this is not something that the child did, but the mum gave him something and he kind of rejected it and took it away. So, I have written down that I thought his message was, 'I do not want that.'"* While reviewing the mothers' boards, the therapists identified various comments that needed to be corrected; such as those that were more focused on higher stages, negative interactions, over-crediting moments, or had different interpretations of the interaction. For example, T03 remarked that *"They have picked a moment where the interaction is not as good and said that it is interaction and modelling. So, they picked positive things out of it whereas we did not feel that that was a particularly good interaction. Because it was interaction on the mum's terms, rather than the child."* Accordingly, the therapists recognised the demand for establishing dialogues for feedback.

6.6 Discussion

In this chapter, we presented a contextual understanding of the PACT therapy protocol that highlighted a number of the practices' values and issues. The coaching techniques adopted in the PACT programme are aligned with the theoretical foundations of health and family coaching (Olsen 2014; Allen & Huff 2014; Rush et al. 2003). Families' coaching was defined by Rush et al. as an interactive process of collaboration between the coach and coachee to promote skills development in natural settings. This collaborative relationship was clearly revealed in the PACT sessions, where the parent and therapist worked closely together to discover and promote more successful parent-child communication moments. The PACT programme reinforced the main three key elements of coaching: allowing personal discovery, which was facilitated through the video reflection conversations; focusing on improvements within the parent-child interactions; and adopting flexible and individualised coaching processes. The importance of the conversations has been revealed through the therapy session in order to understand the parent's personal knowledge behind the parent-child interaction, plan for the next activities, and emphasise the significant role of the parent in this coaching process. The collaborative conversations and relationships between the parents and the therapists resulted in flexible therapy sessions that were organised based on the captured interactions and the flow of their conversations.

The contextual study revealed the PACT principles associated with the central elements of the coaching process: observation, action, and reflection (Rush et al. 2003). The observation phase in the PACT therapy was presented in different forms, which centred around the video recording and included the therapist observing the parent-child interaction, the parent self-observing the parent-child interaction, or joint observation. Video-based observation of the interactions is considered an essential element of the PACT protocol. As confirmed in previous studies (Kennedy et al. 2011; Fukkink 2008; Schrader-McMillan et al. 2012), the use of video-based feedback in the coaching process is shown to enhance the parents' skills and perception of the child's communication, promote more positive behaviours, improve the development of the children, alleviate the parents' stress, increase self-confidence in parenting, and increase enjoyment by recognising successful interactions.

The action phase of coaching in PACT represents both teaching new practices that are introduced by the therapists, and the self-identifying of goals and strategies by the parent. Although the parents are encouraged to self-identify their goals, the coaching process in

PACT is heavily based on the parent's criticality level, learning style, and self-esteem, which might enforce the need for different levels of therapist guidance. Finally, the reflection phase in PACT is where the therapists support the parent to adopt self-coaching practices in their life routines to maintain continuous improvements beyond the therapy programme and promote generalisations of practices by the child and other carers in different interaction scenarios. Additionally, the PACT therapy programme represents a recurring and evolving coaching process that does not follow a linear coaching path but is built on naturalistic behaviours and expands beyond the coaching programme time frame. This is also confirmed in the literature, which describes health coaching as a nonlinear process to achieve the desirable goals and result in a sustainable behaviour change (Olsen 2014).

Even with a self-coaching technology, continuous support from professionals is found essential. The video annotation boards activity helped us to identify the challenges associated with parent's independence reflection, which includes falling into old behaviours, lack of reflection, and their tendency to focus on negative interaction moments. Additional risk factors were revealed from the contextual exploration that involve stress, frustration, and lack of engagement with home therapy practices. Social support and parent-centred services have been confirmed to increase the adaptability and reduce the stress levels of parents of children with ASD (Baker-Ericzn et al. 2005; Boyd 2002). Other forms of social support have been revealed in the ePACT study, these extended to other family members and caregivers, where the parent felt more confident and empowered with improved competencies to interact with their autistic child and share the learned knowledge and achievement within the child carers' network. Social support showed a bidirectional benefit that influenced the parent's motivation and extended the learned experiences in the environments surrounding the child in order to ensure generalisation and promote the child's development (Liu et al. 2011; Kientz & Abowd 2009; Kientz et al. 2009).

However, the study revealed that substantial barriers exist to making effective social communication with professionals and the child's caregivers, which results from the lack of solutions that fits the therapy practices and the existing family dynamic for remote support and file sharing, along with the supporting information flow between the parent, therapists, and the child's caregivers. The remote sessions delivered through Skype was intended to support the parents to adapt therapy practice in their natural environment and maintain their engagements and skills. However, these remote sessions were still perceived by the parents as

a remote coaching session rather than to support real practices at home. Moreover, remote coaching via Skype identified challenges concerning file sharing, review, and reflective discussions.

Consequently, we found that self-coaching technology must be designed to preserve the value of coaching and PACT practices (dialogue, partnership, video-based reflection, parent-oriented, empowering, recurring, facilitating generalisation); promote various level of social support (professionals, family, caregivers); and have a positive impact on the parent's behaviour change and wellbeing (empowering, limiting stress, encouraging). Regardless of the therapist support level, digital solutions have the potential to be used with the parents experienced with PACT therapy, either during and in between therapy sessions or in the post-therapy phase to maintain their skills. Designing a remote coaching technology is also considered an opportunity for the professional therapist to monitor the parent's progress with the learned practices, as well as to have a better conception of the interactions and challenges in the real environment.

6.7 Summary

This chapter has described the ePACT case study and the results of the first design phase which outlined the experiences learned from existing therapy protocols and the potentials of technology to support self-reflection practices. Through the contextual exploration, we presented parents' and therapists' perspectives, experiences and challenges faced in the indirect therapy programme (related to RQ1). We also confirmed the importance of the therapist support in the self-coaching solution. Although the PACT therapy programme is considered flexible in its way of coaching techniques, there is a specific structure of stages and strategies that the therapists follow as guidelines to progress the parent through the programme. Therefore, the next design step is intended to move forward and explore more about the actual role of technology in the therapy process and inquire into the required representation of the therapy structure, annotation, and monitoring strategies. In the next chapter, we will introduce the next two phases of the joint co-design workshops for self-coaching technology with the mothers and therapists and discuss the design considerations related to these technologies.

Chapter 7. Co-designing ePACT

7.1 Introduction

The contextual exploration in the previous chapter showed the effectiveness of video engagement practices as a crucial element for reflection and coaching in the PACT protocol. While the initial investigation of the role of self-coaching technology revealed the importance of the therapist's role, even in a self-directed coaching platform, in order to provide the needed guidance and support. Even with the experienced mothers, the selection of the good moments in the recorded parent-child interaction proved to be a challenging task as they remained critical and focused on the negatives. Subsequently, these findings reinforced the significance of the continuous professional support for maintaining the achieved level of skills, along with revealing the various opportunities to provide and use self-coaching technology either within or post-therapy.

Moreover, as we saw in the previous chapter, PACT programme follows a specific structure of strategies and stages that the parents progressively achieve, based on the therapist's assessment. Consequently, we realised the need to further investigate the role of technology to represent the PACT protocol, in addition to facilitating data capture, annotation and reflection practices. Therefore, in this chapter, we describe co-design sessions that were conducted in order to drive these design decisions before developing the actual system prototype (Phase 2); these were then followed by design goals generation for a self-directed coaching technology (called ePACT); and a design critique workshops to reflect on the preliminary system design (Phase 3). Therapists and mothers were jointly engaged in the co-design workshops; this facilitated achieving agreement on the design elements based on their roles and experiences. The chapter then ends with design considerations and opportunities for digital technologies to support parent-led video feedback practices.

7.2 Phase 2: Study Design

The second phase was aimed at exploring the design options and establishing agreement on the key design concepts for the self-coaching technology that would be the basis for the preliminary design. One two-hour joint design workshop at each location (with mother and

therapist participants) was conducted to scaffold the design discussion and explore the required design features. The Newcastle workshop involved two therapists and two mothers, while the Manchester workshop was held with two therapists and four mothers. In these workshops, inspirational design cards and storyboards were used to facilitate ideas generation and discussion.

Inspirational technology cards were used to establish a focused design dialogue and narrow down the future design options, while allowing extension of the initial design ideas according to the participants' perspectives (Halskov & Dalsgård 2006). The findings from the contextual phase (Chapter 6) informed the design of inspirational cards in four separate tasks for data collection and reflection process. These tasks are replicating the scenarios of PACT sessions, which involves video capture, video annotation, reflection, and monitoring. Building on the outcomes of the previous phase, there was a mixed use of smartphone or external camera to capture the videos, and the portability of the annotation was deemed important for the parent's lifestyle. Therefore, two sets of scenarios cards were designed with different technologies to suggest initial design options where the participants could discuss the technology elements more precisely. Each card focused on a specific task; a general explanation of the task, along with the devices used, was written on the back of the card.

Scenario 1 (the blue cards in Figure 25), represented the use of a smartphone camera to capture the interaction, along with a Bluetooth button to start, stop, or mark moments in the video recording. Annotation, reflection, and progress tracking scenarios were all represented using smartphones or tablets. For annotation, the scenario explained the possibility of marking moments, comments, and strategies. The reflection scenario generally explained the way of reviewing an annotated video by the therapist and/or mother, while the feedback scenario explained the ways to track and represent progress quantitatively based on the strategies practised. Scenario 2 (the green cards in Figure 25), represented the use of an external video camera to capture the interaction, along with a Bluetooth button to start, stop, or mark moments in the video recording. Annotation, reflection, and progress tracking scenarios were all represented using a TV for the benefit of the wider display screen. The activities scenarios were similar to the blue cards.

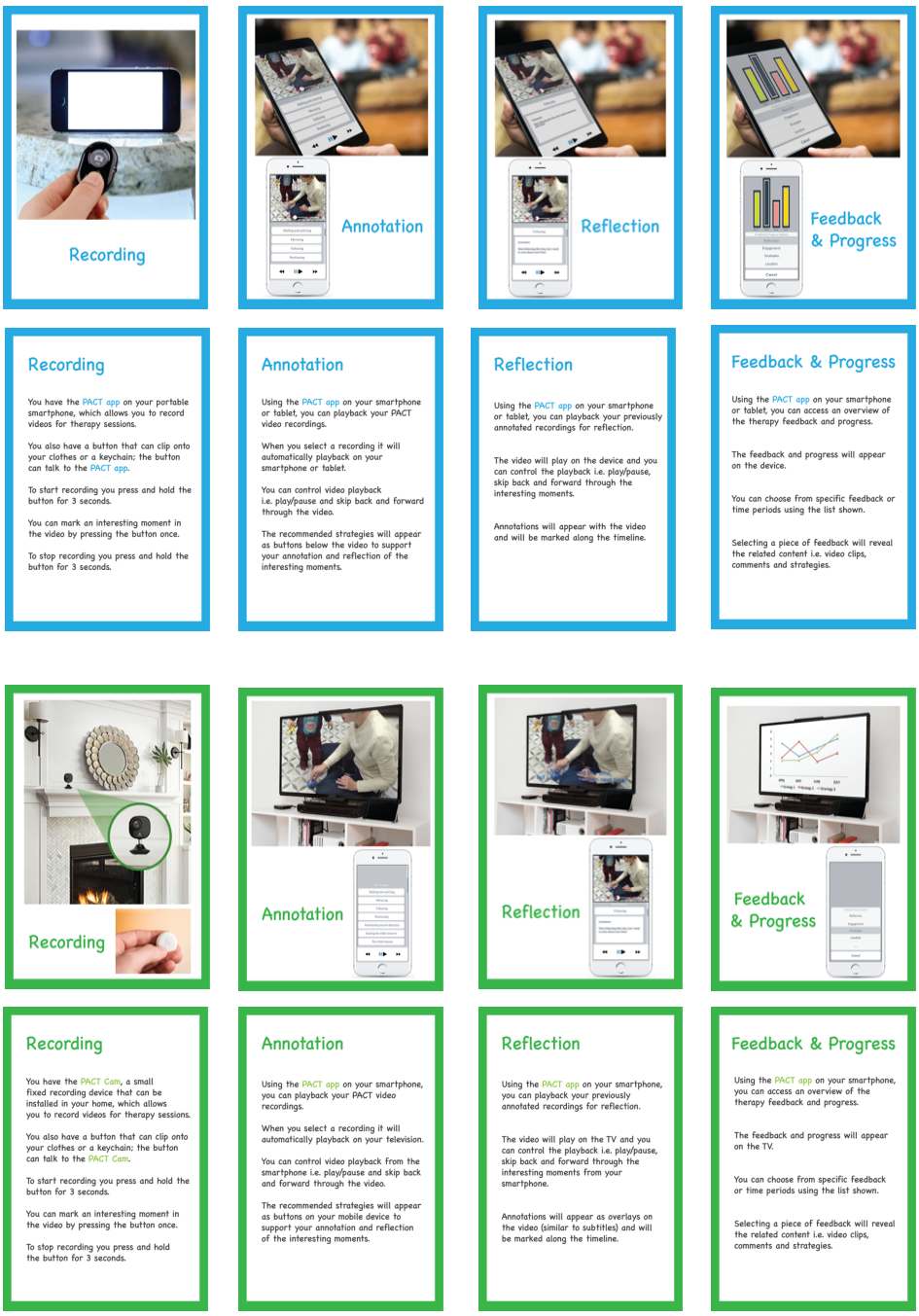


Figure 25. Inspirational design cards

The workshops were structured based on the four activities related to the four main tasks in PACT sessions (i.e. recording, annotation, reflection, feedback and progress). In each workshop, the participants were divided into two groups; where the mothers grouped with the therapists. Each group was assigned a specific set of blue or green cards. In each activity, the participants were given a specific inspirational design task (based on their group colour), along with blank storyboard sheets. The storyboard sheets were used to allow the participants to sketch or write the narrative about their thoughts on how they imagine the proposed

solution will work in their real-life practices, including the challenges that would possibly be faced (see Figure 26). At the end of each activity, the participants were asked to read the card and explain their use scenario about the task. Consequently, task-based discussion was held to reflect on the participants' stories and compare the design options (blue or green), in order explore the potential design elements. These discussions included the challenges of recording using the Bluetooth button, the practicality of annotation initiated by the therapist, how the strategies were defined in the system, the moments sharing and dialogue establishments, the importance of tracking progress, and the possibilities of the allowing the therapist to remotely monitor progress. The discussion outcomes were used to generate the design goals and develop the mock-ups of the proposed digital solution.

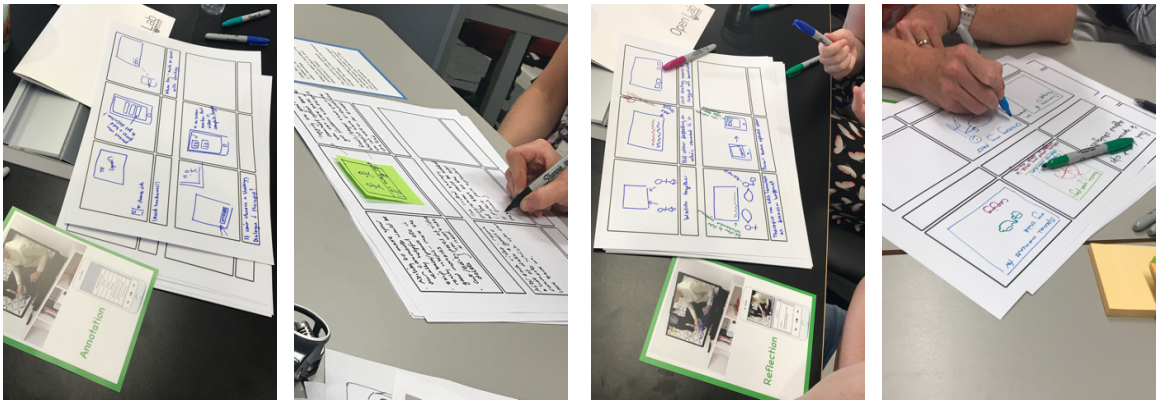


Figure 26. Storyboards of the co-design workshops

7.3 Phase 2: Design Exploration Findings

In this section, we describe the main four themes resulted from the analysis of the co-design workshops discussions. Generally, the findings revealed the need for portable and available devices, simple and meaningful annotation process, provide support and encouragement while limiting stress.

7.3.1 *Looking for Accessible and Portable Devices*

With the smartphone and TV presented as design options for the reflection process, the mothers reported that this option is less practical for them since they either did not own one or were not familiar with it. As P05 commented, *"I have only got one recently because mine broke. I do not actually know how to use it. You do not use these things usually. The kids know how to use it more than me."* Additionally, two possible recording techniques, including

mounted camera and smartphone, were presented during the design sessions, and the mothers expressed their preference for using their smartphone camera. While the fixed camera was discussed to be always set up, ready to capture with a wider angle to cover the full play environment, various challenges were expressed by the mothers and therapists. Initially, the mothers found that a more formal and planned play session would be held with the use of a mounted camera, due to the play setup needing to be within the camera area. With a less portable camera, the play area will be limited to the camera place, fewer generalisation scenarios will be recorded, possibilities to lose the moments will remain, and the recording will be limited to home and will be less spontaneous. For example, P03 remarked:

"As long as it was there, then you could go and record subtly, then that would be great and it would be just in the moment. But then the other flip side is, you are in the garden, and the camera is in the house. By the time you have gone to get the camera, the moment has gone and your child would notice."

Installing cameras everywhere in the house was suggested as a solution, but the mothers expressed how intrusive this would be to the family's privacy, and how it would result in the recording of artificial interactions due to parent anxiety. Moreover, the mothers expressed worries about the cost implications associated with the camera compared to the use of their personal smartphones. For example, P04 remarked, *"I think that would be the least expensive option because everyone has a phone, whereas to buy a camera … you spend enough money on your child… So, the mobile would the cheaper option."*

Mothers and therapists thought that with the smartphone camera it would be more possible to capture spontaneous moments everywhere, either inside or outside the house, due to the phone availability. The mothers expressed how they were always connected to their phone, and were into the habit of video recording using their phones. As P02 commented: *"I am never two seconds away from my phone… So, I would look at places where I would set it up if I was using it at home and then we do a lot of sessions in the bath, maybe just put it on the wall and then start playing with them or maybe like a Velcro, where you can stick it on wherever you are, around the house obviously, to capture various sessions."*

Meanwhile, the therapists reported that more generalisation would be captured. As T02 said, *"You would get more spontaneity and more generalisation with this video because you could*

do it, like, say, in the bath or if you were in the garden." Moreover, the mothers and the therapists stated that with the smartphone it is easier to record, edit, and reflect on the video using the same device, instead of the need to transfer the file when an external camera used. As T04 explained, *"The extra step of having to record a video and then send it on to someone with the video camera you are creating another step ... Whereas, if it is on your phone you can share it much more easily."* Some of the mothers (n = 5) added that it is easy for them to trim the video using their smartphones if needed.

7.3.2 *Explicit vs. Vague Protocol*

One of the central discussions was around how to tag and annotate the moments with meaningful comments related to the PACT principles. There were some debates between the therapists in regard to how the stages would be presented to the parent through the tool. Some of the therapists (n = 2) wondered how the parent would value having the whole PACT programme explicit with all stages and related strategies presented through the system, which they thought might be helpful for some parents to easily select the relevant one for each moment. On the other hand, some therapists (n = 3) thought that this would make the parent more prone to erroneous judgments, because in reality the progress might fluctuate between stages, or the parent might jump to higher stages or practise strategies that did not work with their own way of interacting with their children. As T01 remarked:

"If their kids are verbal, if they had free choice of where to go in the strategies they would pitch it far too high because they would think, 'He is talking, I am going to go to stage 5 strategies.' But actually, they still need the fundamental principles to happen from stage 2. Equally, you would have other parents who would go, 'I have done five out of the six strategies at stage 1, but I have not quite got this one, so I am going to keep sticking and sticking,' and that might not be a strategy that actually works for their child."

The therapists (n = 2) added that defining the parameters of progress or success through the PACT stages is hard, since it is based on professional assessment and personal evaluations. Therefore, the therapists (n = 3) believed that the stages still had to remain under their control in order to progress the parent, as well as to remain vague for the parents to avoid introducing additional pressures. Since the progress through stages is not linear, some of the mothers (n = 4) confirmed the possibility of added stress due to the resulting fluctuation or frustration if the parent remained longer in one stage. Therefore, even if the mothers felt curious to explore the

stages and relevant strategies, they (n = 5) confirmed the associated anxiety and progression difficulties. For example, P06 said:

"How if you did it could be quite a worrying experience because you could think, you are suddenly at six and now you are back at one. But then the week after you could be back at five and why is that helpful really? I would be wanting to align them with strategies, I just would not be wanting to be bothered about progressing through the stages."

7.3.3 *The Demand for Meaningful Annotation*

As for the video annotation, we expanded the discussions from the previous contextual phase to further explore the required representation of stages and strategies. In this design phase, the mothers said that it would be practical to start with tagging the moments with the relevant strategy, and then add further reflective comments at any time later on the day. For the strategies tag, some of the mothers thought it would be useful to have a unified list of PACT strategies, with an added glossary for each strategy. Thus, it would be easier for them to select the related strategy and ensure that they added the moment to the right category. However, the mothers did not use any formal strategy name in the annotation boards as discussed in design phase 1. The mothers (n = 2) explained that they used to forget the actual strategy name and that the strategy name was not descriptive, so they needed to revisit the video to understand the strategy.

With an explicit list of strategies, some mothers (n = 3) expressed the risk of over-tagging the video with many strategies, rather than focusing on specific strategies each time. The therapists suggested progressively revealing the strategies to the mothers through the system in order to avoid overwhelming the parents with many strategies that had not yet been introduced to them or were not tailored to their model of interaction. Consequently, a personal list of strategies would be established for each parent which they could revisit when needed, as T02 explained: *"I think keeping the previous strategies is really important because as you move through the stages, lots of my parents, we get to stage 3 and all of a sudden, you have to think, 'Hang on a minute. No, you have completely forgotten what we have talked about at stage 1.'"* The therapists (n = 4) also discussed the importance of not restricting moments to strategies in order to create open dialogues and introduce new strategies, as T03 remarked, *"Sometimes the strategy you want is not there or that you do not actually know what is going,*

so you would click an 'other' and that might start a little dialogue with the therapist where you can be, 'I like this moment, but why?'"

As for adding comments, some mothers (n = 3) and therapists (n = 2) explained that this process would provoke reflective thinking. While conducting the video annotation task, the mothers (n = 6) reinforced the importance of watching the video recording without being obliged to add any annotations. Consequently, the mothers felt that in the second round of watching they were able to think deeply and identify the small spontaneous interactions.

7.3.4 *Risks and Benefits of Collecting Moments*

The therapists (n = 3) expected one of the rewarding outcomes of a self-reflection tool to be the ability for the parents to establish a personal moments library, containing a collection of good interaction moments that they can use to remind themselves of the strategies, or for self-motivation when progress is noticed. Some of the therapists (n = 3) explained that they used to verbally remind the parents about successful practices and moments as visual media were not accessible to them. Additionally, the therapists (n = 3) found that some mothers were not able to see small/cumulative progress or got frustrated when the child plateaued; therefore, they felt that establishing this library would help to encourage the mothers or point them to previous progress. As T02 expressed it: "*Almost like a 'See how well it is going,' because when it is going really well, it just becomes part of your day and actually you need to look back and think, 'He was not like this three months ago, he is making progress.'"* Additionally, the mothers (n = 5) suggested that a moments library would help them to look at the overall progress for self-encouragement, remember how to play with old toys, review examples of practices, or reflect on the challenges faced during the week to plan their next actions. For example, P02 said:

"If you find something is not working and he is having more meltdowns, then you have always got that app to go back on and think, what is going on? And then think, 'Ah! right, I have been talking too much there or I did not give him enough time to respond before I asked him another question.'... Sometimes, it is nice to just go back six months and think, 'Blimey! Look how far we have actually come. Give yourself a pat on the back. Stop being so hard on yourself and sort of carrying on.'"

Moreover, the mothers (n = 4) expressed how the archived moments would help them to teach other caregivers and become more self-empowered. For instance, P06 said: *"You are left with almost like a video album of best moments in all the different strategies, which could be shared with other family members or teachers. And they can learn tips from watching the videos. Maybe you are in a bad patch with your child or something and actually you can click on mirroring and see this wonderful example of yourself doing great work with your own child. And it would just be quite empowering, I think, and helpful and comforting, if that was possible."*

Equally, the mothers (n = 4) were against collecting and summarising any progress details in a quantitative manner. Some of the mothers argued that it is meaningless to show the number of times they practise a specific strategy, yet they suggested it would be useful to show if the strategies were practised or not. For example, P05 said, *"I often did do that myself. I did not do a lot of mirroring at one stage, I was doing more of the other, so I remember she told me, 'Try and do some more mirroring as well.'"* The mothers were all unanimous that the word "progress" and quantitative representations were sensitive due to the associated sense of failure. The therapists also confirmed the risk of demotivating the parents since progress is not measurable nor linear, as T02 explained: "*The progress is not linear. Everyone has bad weeks or bad months, or the children or parents are poorly, and we just would not want anyone to get disheartened."* Another possible risk expressed by the therapists (n = 2) was the possibility of encouraging wrong behaviours. As T03 commented: *"Like, Stage 2 has commenting not questioning strategy, and it has reduced in the language input, so you could have a mum going, 'Yes! I am commenting all the time.' But, actually, they are bombarding them with language input that they need to strip away, but they are filling up that progress bar of how many comments they have made."*

According to the therapists' experiences, the PACT protocol is focused more on doing the right strategy at the right time than on doing all the strategies all the time. Thus, the therapists (n = 4) reported that quantitative representation of the strategies practised per week might be frustrating for the mothers, as T04 explained: *"I would not want it to be like a, 'Oh I did a crap job parenting my child this week because my graph took a dip', where actually there was real-life stuff going on."*

7.4 ePACT: Self-Coaching Technology

Based on the findings of the previous design phases, we introduced ePACT as video-based self-directed coaching tool designed to promote the parent's self-reflection skills. ePACT can be used as a self-coaching tool in different situations, including 1) in between therapy sessions with various levels of support based on the parent's need, 2) as a replacement for the current Skype sessions, 3) in-session to reflect on the moments self-collected by the parents with more realistic examples from their real environment, and 4) in the maintenance phase or post-therapy for more independent parent practices. In this section, we introduce and discuss the design goals of ePACT in response to the design engagement activities outcomes along with previously applied studies which inspired the different features of the tool. Finally, the ePACT design is presented, with scenarios and mock-ups.

7.4.1 *Design Rationale*

The current PACT practices encourage parents to generalise the learned skills in their natural practices with their children and capture them in video recordings. However, these home practices are challenged by a lack of practical technologies to support the data capture and sharing, along with the need to empower the parents' skills of self-reflection and independence while gradually reducing their reliance on professional feedback. Thus, it is important to ensure that any technologies designed to support self-directed coaching are easy to use and do not add stress to parents' current practices and daily care routines.

Based on the findings from the series of workshops, we developed five design principles for mobile technology to support the needs of parent-delivered therapy and promote self-reflection skills. In this section, we describe the specific design principles of ePACT. These include re-appropriated selective data capture, promoting self-reflection through annotation, a seamless protocol and an informal coaching channel, self-motivating technology, and data sharing and control.

DG1. Re-appropriated Selective Data Capture

Capturing the parent-child interaction is considered a central element for reflection, assessment, and setting goals for communication improvement. Capturing interactions in true comfortable settings at home provide a real communication examples recorded without having any barriers that distract the interaction, such as having a visiting therapist around. In PACT practices, the parents were familiar with capturing their interactions using

smartphones, which they found practical to use whenever a parent-child playful engagement began. However, the parent cannot predict where or when the actual engagement will start. Therefore, mobility and usability are key design considerations for interaction capture technology in such settings.

Various recording technologies have been introduced for data capture and assessment in different settings. These include selective archiving of predefined segments of recordings triggered by the user using mounted cameras and microphones (Hayes et al. 2007; Kientz et al. 2008; Hayes et al. 2008; Hayes et al. 2005), continuous recording using mounted cameras along with a remote button to mark specific problem behaviours (Nazneen, Rozga, et al. 2012), automatic and frequent capture of photographs using a wearable SenseCam (Nguyen et al. 2009; Marcu et al. 2012), and specialised recording devices and buffering systems for continuous recording (Kientz & Abowd 2009; Kientz et al. 2009). Regardless of the successful experiences of data capture and access presented in these studies, it was not considered cost-effective for ePACT to employ the required devices and installations. Balancing the social, technical, and practical aspects of a data capture solution for home practices is an important element to consider while designing any capture solutions (Kientz et al. 2008; Hayes & Truong 2009).

The design of capture technology should consider the following factors: capturing the video data in different ways due to the various environments data will be captured in, having no physical barriers due to the static setup (Aggarwal et al. 2015), allowing the parents to wait for the play opportunities rather than forcing them, enhancing the parents' existing experiences of video capture and watching, and making the process more pleasurable. Therefore, we suggest combining and re-appropriating the features of selective capture technologies and leveraging the parents' own smartphones and past experiences with video recording for data capture. The capture technology should not interfere with the playful interaction between the parent and the child. Therefore, the smartphone should be installed out of the child's sight to avoid distractions (e.g. using a Gorilla tripod to mount the phone in surrounding objects while allowing capture of the parent, child, and play context) and should be controlled remotely (e.g. using a wireless selfie-button). Consequently, the cost and burden of recording will be reduced, which is considered a requirement to promote adoption of technology (Hayes 2006). Although the selective data capture of specific time frames has proved its potential in previous studies (Nazneen, Rozga, et al. 2012), the reflection practices

of the PACT protocol require getting all the data to assess the interaction; yet the interaction period with autistic children is considered short. Thus, allowing a controlled automated capture can ensure getting all the data, if the parent can start and stop the recording remotely when the child is engaged in a play session. With the smartphone camera on all the time after the setup, by remotely controlling data capture the parent can avoid missing recording any moments. Additionally, communicating the recording status through an on-screen notification or control button vibration is important to reassure the parents.

DG2. Promote Self-Reflection through Annotation

Reflection on captured parent-child interaction is a critical element in PACT therapy in establishing an understating of the child's action and any relevant triggers. These reflections are found to be based on selecting good moments of interaction, then establishing a reflective discussion facilitated by probing questions asked by the therapist. These probes vary based on the parent's learning style and the actual interaction elements, including verbal communication, gestures, facial expressions, and/or surrounding objects. In order to facilitate self-directed reflection, the technology should support the parent in less systematic ways to allow them to slow down their thinking process, value the moments in interactions while re-watching, and improve their comprehension of the situation. The parents usually expect communication to be only using words; by reflection small interaction moments, the technology can help them to realise the other natural communication signs, such as eye contact. Previous studies have revealed the abilities of parents to reflect on captured data, which allowed them to see what they had missed in the situation due to the immersive playful interaction, subsequently helping them to understand their child's needs (Marcu et al. 2012). However, self-reflection abilities are considered a challenge for inexperienced people (Mamykina et al. 2008); thus the technology should provide tools to facilitate reflective analysis and consider the individualised experiences.

The remote-control button would be utilised to facilitate reflective thinking by allowing the parent to initiate and identify specific moments based on their evaluation of their significance. While recording, whenever a specific positive interaction happens, the parent can mark the moment using the button for later review and assessment. Live tagging will support the parent in marking their "in the moment experience", adding reference points for them to easily access these moments. The parent will be able to start the initial step of learning, using the button for annotation and in-play reflection. Nazneen et al. (Nazneen, Rozga, et al. 2012)

showed that parents were able to flag specific behaviour of interaction with only minimal training (Nazneen, Rozga, et al. 2012). Furthermore, regardless of the varying quality of the captured videos, the therapists found them useful for discussion even if they did not show the full interaction; this would promote the parent's thinking about what happened before or after a specific action. Therefore, the tool should allow the parent to export small interaction moments, based on the marked moments which they believe useful for assessment.

Moreover, the self-directed coaching technology should be individualised to the parent's experiences, as in the real PACT therapy practices, without enforcing therapeutic protocols or terminologies. Thus, another tool to facilitate reflection is to provide the parent with techniques to easily manage their target strategies and annotate the marked moments with relevant strategies and comments. Video annotation has proved its capabilities in various applications to tag videos with relevant temporal, physical, or contextual information (Fagá-Jr et al. 2009; Patel & Abowd 2004); yet for PACT therapy, annotation refers to the parent's strategies and goals. The parent can gradually establish a personal library of strategies as they progress in the therapy programme, using their own language to populate and tag the recorded interaction moments. With the ability to tag the moments while recording, the parent will be able to shift the burden of reflecting on these moments onto their comfort time (Hayes et al. 2008), when they can concentrate more on selecting the suitable moments for discussion and annotating these moments more effectively with strategies and comments. In addition to the benefit of promoting reflection, the in-action tagging and the open annotation will help to empower the parent with reflection tools and improve their confidence and skills; reducing their reliance on therapists (Aggarwal et al. 2015; Hayes et al. 2008) while also maintaining simplicity, which is a key to facilitating situation assessment (Hayes et al. 2008).

DG3. Seamless Protocol and Informal Coaching Channel

Given the overwhelming nature of caregiving and the various therapy services delivered, a key design element in any self-directed coaching system is to avoid adding burdens or stresses to the parents' existing practices. Thus, a self-directed coaching technology should simplify the home therapy practices and provide access to the needed level of support from the professionals. Although the PACT protocol consists of several stages, these are invisible to the parents; progressing the parents to the next stage is decided by the therapist, with the possibility to move back and forward between stages as needed. Therefore, the technology should replicate the existing coaching programme and break it down to be simple with a

gradual focus on strategies. With invisible and seamless stages, the added pressure of progress will be eliminated.

On the other hand, continuous knowledge and social support, especially for inexperienced parents, have been identified as crucial and confirmed in the literature (Liu et al. 2011; Schorch et al. 2016). In ePACT study, the professional support was found useful by the parents for different reasons. For example, to provide emotional support when they were going through the emotion of reflection, to overcome frustration which resulted in a lack of commitment to the home practices, to steer their focus towards the positive interaction moments when they fell into their old habits of being critical, to promote skills practices where they could get bits of advice and progress, and to learn new strategies or techniques. The value of support was well recognised for establishing a trustful relationship with a professional, which reduces stress and facilitates therapy adoption (Aggarwal et al. 2015; MacKintosh et al. 2012; Baker-Ericzn et al. 2005). The alternative service delivery model is a well-known mechanism to train parents or provide remote support (Meadan & Daczewitz 2015; Mamykina et al. 2008; Hayes et al. 2014). However, these models have been focused on synchronous communication.

Therefore, the design of self-directed coaching should allow access to professional support by re-appropriating the design of familiar messaging applications for specific interaction moments when shared with the therapist by the parents. With asynchronous conversation-based messaging, the demand for prompt responses from the therapist will be reduced and the existing coaching dialogues can be replicated remotely. Additionally, the remote communication will provide a way to jointly watch a video whilst chatting, which is not possible in live remote video communication. The informal remote coaching channel provides a continuum of therapy inputs to deliver guidance, assurance, motivation, and so on. There are several added benefits from the therapist's side. Firstly, having a backup tool between sessions will help in monitoring the performance of the parent and the child and ensuring correct generalisation. Secondly, it will provide them with a way to leave the parents with a visual session summary, when the reflection and annotation tool is used during the therapy visits. Additionally, the remote coaching channel will provide the therapist with ways to deliver therapy services to people who are not able to receive visits due to their geographical location or scheduling challenges (Meadan & Daczewitz 2015). Finally, with coaching discussions documented in a portable and visual tool, the narrative voice of the therapist will

be easily remembered by the parent after the programme has finished, which is important for the parent to remain engaged in these practices.

DG4. Self-Motivating Technology

As the therapists stated, the progress of the communication development skills of children with special needs is often slow and difficult to trace compared to typically developing children. Therefore, children with language delay might not achieve the top level of verbal communication, while the parents usually have higher expectations and are stressed and anxious about the future and how to help their child's development (Hinojosa 1990; Hinojosa & Anderson 1991; Baker-Ericzn et al. 2005). The study showed that when the parent sees the value and impact of home practices, they continuously commit themselves to repeating these practices, and vice versa: with the parent repeatedly doing the home practices, the child's communication skills will be improved. Therefore, there is a need to identify ways to motivate repetition and encourage the parents when the progress has plateaued.

Comparing progress against strategies milestones was revealed to be stressful. The participants were also reluctant to track progress in a quantitative manner, such as via the number of times they practised a specific strategy in a week. This is consistent with previous research indicating that record keeping and tracking cause stress for the parents of young children (Kientz et al. 2009). Even the word "progress" is quite sensitive to use in this context because the child's communication skills fluctuate between stages and are highly dependent on the child's mood and other health factors, which might result in the parents having a feeling of failure. Thus, coaching technologies should allow self-motivation and encouragement, based on the collection of the captured moments, without increasing stress.

Due to the immersive nature of special needs and caregiving, the parents tend to forget their previous achievements and successful communication with their autistic children. Visual media have proved their capability as memory cues to recall past events (Hodges et al. 2011; Conway 2005; Sellen et al. 2007). With the recollection of past events, the related feelings, experiences, and emotions are realised again (Hodges et al. 2011; Conway 2005). Several development-tracking technologies support tracking and sharing of achievements of development milestones with other caregivers, which the parents found rewarding (Kientz et al. 2009; Kientz & Abowd 2009; Hayes et al. 2014). Therefore, the design of a self-directed coaching system should allow the parents to mark the captured moments that exemplify a

successful adoption of a strategy or show a communication achievement. The interaction feedback and the child responses are the true engagement for the parents, so logging these moments will let them realise the impact of their persistence with the practices. This will facilitate creating a library of remarkable interaction moments which relate streams of moments without human effort. The video library can facilitate access to good examples of practices for self-encouragement or to share them with other caregivers. The system can also auto-motivate the parents by generating notifications to review the past moments of achievements as "flashbacks".

DG5. Data Sharing and Control

The parents learned skills, practices and experiences throughout the PACT therapy programme, which resulted in realisation of their expertise and self-conception of themselves as therapy experts. This is consistent with previous studies showing the self-positioning of caregivers as care experts (Schorch et al. 2016). As a result, the parents try to play the therapist's role within their social network and coach the caregivers of their child to adopt the learned techniques and strategies. The parents also showed their interest in coaching other families of children with autism; however, establishing trust was an important element in order to share sample videos of practices. Therefore, the technology should empower the parents and support their role as care experts by establishing social support channels with the other caregivers and peers. With the social support channel, the parent would be able to share examples of strategies and practices as video segments, along with annotations and comments. Similar to the professional support channel, the parent could also establish conversations with the caregivers and discuss the practices shown in the captured moment. In return, the parent can realise their expertise, gain confidence, and ensure the generalisation of the adoption of strategies by all the communication partners of their child.

However, video recording in true environments is considered to involve private information and is associated with intrusion risks for other family members. The privacy concern relates to the media shared either with professionals, family, or peers, and control over the data is a well-recognised design consideration in similar systems (Hayes & Abowd 2006; Nazneen, Rozga, et al. 2012). Thus, the designed coaching solution should provide the parent with full control over the media shared by providing them with techniques to manually edit the video segments before sharing, to recall the access permission whenever needed, and to protect the shared media from being exported beyond the coaching system by the recipients.

7.4.2 *Design Scenarios and Mock-ups*

ePACT was designed as a smartphone application for self-directed coaching, based on the design goals discussed in the previous section. The design was developed using Adobe XD to build an interactive mock-up that could be easily reviewed by the participants, either using smartphones or desktop computers. ePACT facilitates the five main tasks for video capture and reflection: capture, annotate, review, share, and archive. In this section, we will introduce the design scenarios and mock-ups of each task in relation to the design principles. The application is to be used similarly by both therapists and mothers; however, the use case scenarios are explained from the side of the mother as the main initiator of the coaching process.

Video Capture

In ePACT the main element for reflection is video recording of the parent-child interaction. ePACT facilitates the video capture from within the application. With the benefit of the mobility of a smartphone (DG1), whenever the mother notices a good time to play with her child she can set up her smartphone using a tripod in a position that allows the capture of mother, child, and play objects. The smartphone camera can be positioned in landscape or portrait mode (whichever provides a better view of the area), and the mother can use either the front or back camera as preferred; to avoid screen distraction, for example. After mounting the device, the mother can start the camera from the ePACT app, connecting the Bluetooth selfie-button, as shown in Figure 27.b. The parent then can leave the camera on and hold the control button while playing with her child. Whenever the play engagement starts, the mother can double-click the button to start recording, as shown in Figure 27.c. While playing, and when the mother notices a good interaction moment or an interesting moment to review, she can click the button once, which will time-tag or bookmark the moment in the video recording (DG2). This can be done repeatedly when other moments are observed, to mark them for later reflection. At the end of the play session, the mother can double-click the button to stop the recording and save the video to her ePACT video library, as shown in Figure 27.d (DG5). Alternatively, the mother or the therapist will be able to connect an external camera to synchronise the video recording, using the “Pair to Camera” option as shown in Figure 27.b. This is deemed useful especially during the therapist visit, if the therapist prefers to use their personal camcorder instead of a smartphone (DG1).

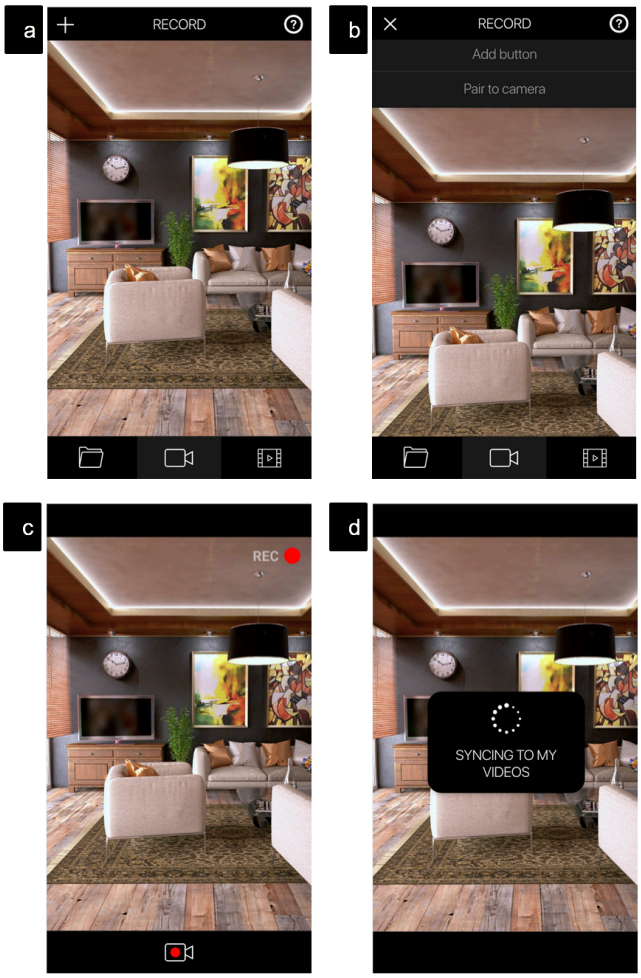


Figure 27. ePACT video capture scenario

Annotation

All of the recorded videos will be listed on the main screen of ePACT, ordered with the most recent video first, along with vertical blue lines on the video snapshot to represent the tagged moments within the video (Figure 28.a). The tags are coloured based on the user (blue for mother, pink for therapist). Video annotation can be conducted anytime and need not be done directly after the video is recorded (DG2). The mother can select a recently recorded video (video at the top in Figure 28.a) in order to re-watch the interaction, review the marked moments, adjust the moment duration, add an annotation to each moment, or delete a marked moment if nothing interesting is found (DG2). The video review page will show the video and a list of unnamed tagged moments (Figure 28.b). An alternative view is the timeline view mode, where the tags appear according to the played video timeline (Figure 29.b). In this view, the mother will be able to drag the time bar to the tag to move between tags, and the annotation text will appear at the bottom. The mothers can also add new tags while re-

watching for any other interesting moments that were not noticed during the live interaction while recording the video (DG2).

The mother can select tagged moments from a list, re-watch the related video segment, and add any comments either for her personal reflection or to open a discussion with the therapist (DG2, DG3). The system will allow the mothers to type or audio record their comments in case of literacy or time management issues (Figure 28.c). The mother will also be able to rename the tagged moment to reflect the related strategy (e.g. mirroring, as in Figure 28.d). The strategies' names can be entered manually by the mother, according to the language the mothers use with their therapist to describe the strategy in the home programme. Subsequently, the mother will establish a personalised list of previously used strategies from which they can select the strategy name, rather than using manual entry (DG2). As a result, the mother will gradually progress with strategies without being overwhelmed by a predefined list of practices that have not yet been introduced to them by the therapist or might not apply to the nature of communication and the condition of their child (DG3). Additionally, the mothers can mark their favourite moments of interactions that demonstrate good adoption of a strategy or reaching of an achievement in the parent-child communication. By clicking the start button next to each tag, the moment will be added to the favourites library (Figure 28.b) (DG4). Finally, at any screen, the mother can click "?" to access a help description next to each button (Figure 29.a).

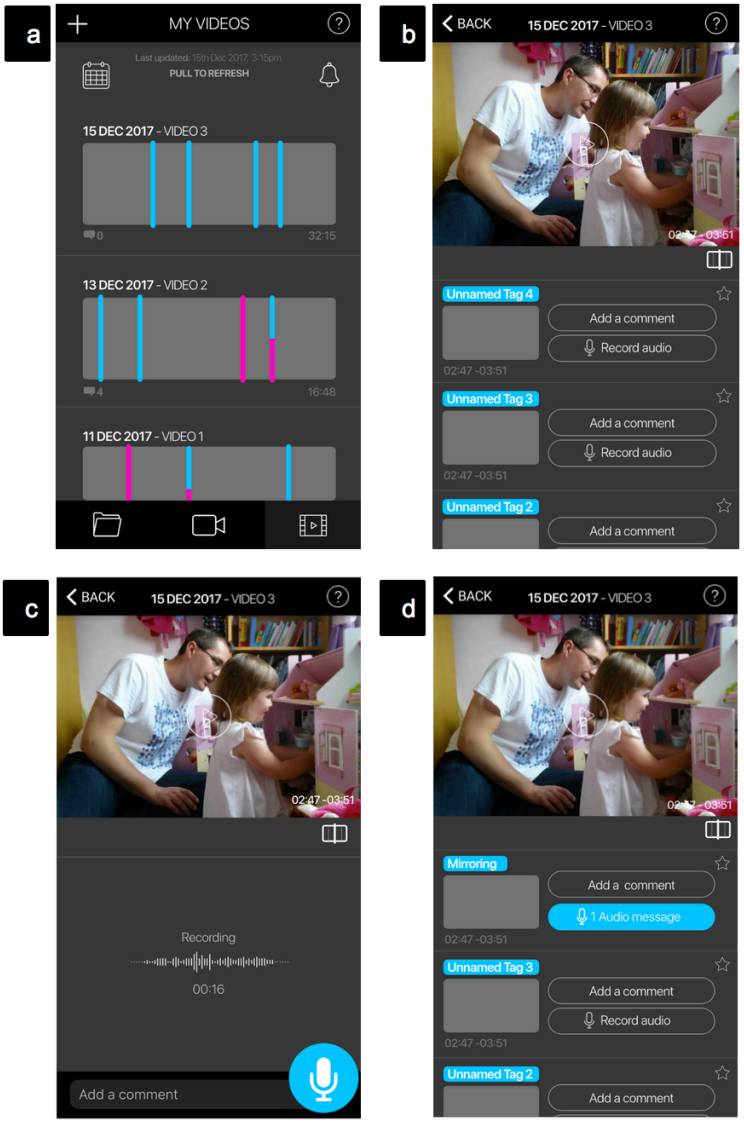


Figure 28. ePACT annotation scenario

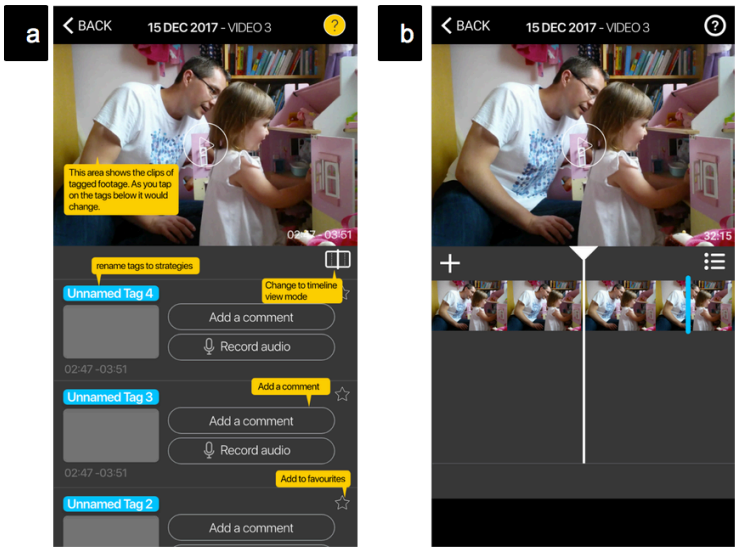


Figure 29. ePACT help and timeline display option

Review and Feedback

ePACT allows the mother to share a video or specific tagged moment with the therapist to access feedback or discuss a concern shown in the recorded moment. Subsequently, the therapist will be able to review the mother-child interaction in their true environment and ensure that the mother is correctly generalising the learned strategies in various communication settings with her child (DG3). The annotation scenario for the therapist is similar to the mother annotation scenario. Based on the assessment, the therapist can decide if the mother and child are ready to progress to the next PACT stage and introduce the stage techniques, either through remote conversation or by arranging for a home visit. Through sharing, the mothers will also be able to access advice and stay motivated through the remote support received from the therapist. The conversation and communication between the mother and the therapist can be synchronous if both are online at the same time, or asynchronous to reduce the pressure of prompt responding (DG3).

Whenever the mother receives a feedback from the therapist, a notification will be shown in the video list homepage (Figure 30.a) and the vertical pink lines on the video snapshot will indicate the moments reviewed or added by the therapist. The therapist will be able to comment on each moment shared or add new tags for moments not identified by the mothers, to bring their attention back to the good communication if they were more focused on negatives (DG3, DG4). This can open a dialogue with the therapist to guide the mother's reflection when needed and allow them to better understand why the moment was good and how to maintain similar moments in their communication with the child (DG2). The mother can review the therapist's feedback from the tags list page of the video (Figure 30.b) and can establish a conversation with the therapist over each of these moments as needed (Figure 30.c) (DG3).

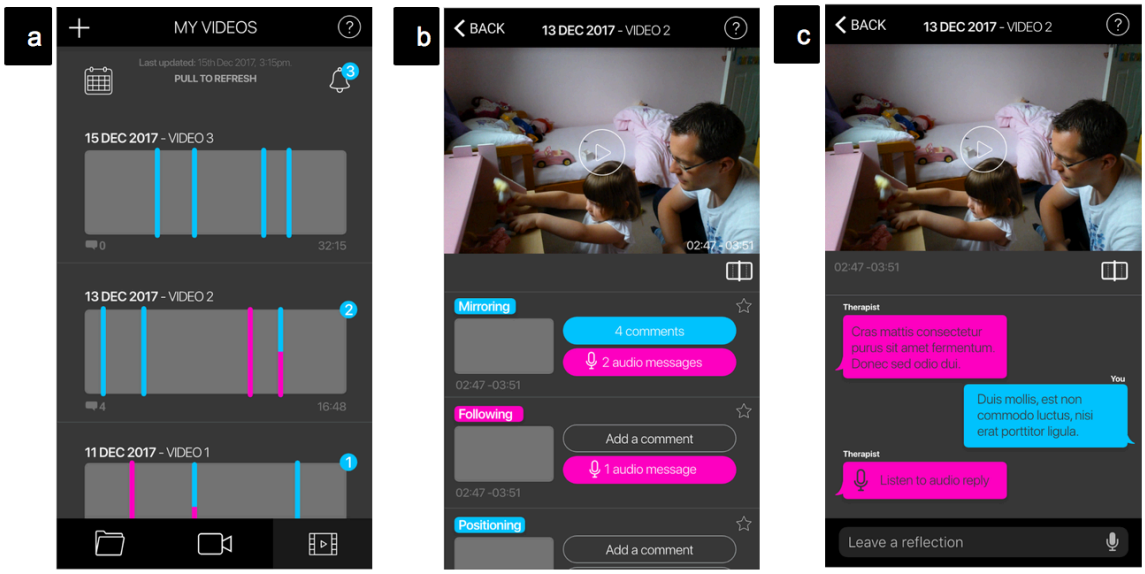


Figure 30. ePACT review and feedback scenario

Sharing

In order to empower the parents and facilitate their interaction with different caregiving partners (including professionals, family members, and learning assistants), the design of ePACT allows them to share recorded moments as examples of interactions or to demonstrate a specific form of interaction preferred by their children (DG5). This also includes sharing the recorded achievements with family members as a self-reward, such as when the child develops new skills (DG4). Sharing video and related annotations remains informal (as in the established conversations of annotation and feedback), to make the system familiar to the parents (DG3). However, there are some privacy concerns associated with video sharing; these relate to social issues (e.g. the appearance of other people in the recording) or experiential issues that the mother might not be willing to share (e.g. mother or child showing negative behaviours). Furthermore, there is a need to avoid overwhelming the therapist with a long video recording and to remain in compliance with the protocol practices (i.e. share one or two videos of 1–2 minutes each). Thus, the design of ePACT allows the parent to edit and select specific moments of interest to be shared (DG5). Consequently, the parent can meet the therapist's request while maintaining their privacy and control over which moments to share. The therapist can also observe and assess the generalisation better when several moments are shared from multiple videos which have been captured on different days or in different contexts (DG3).

ePACT allows the parent to create and share a summary video which consists of one whole video or selected moments from one or more video recordings. By clicking the “+” sign at the top left of the home page, the parent can start creating a summary video (Figure 28.a). First, the parent selects the main video recording(s) (Figure 31.a); then, all tagged moments from the selected videos will be listed so that the parent can select the related ones (Figure 31.b). The parent then can add an audio note to introduce the content of the video summary (Figure 31.c, Figure 31.d). The parent can then save the video summary and share it either with the therapist or with family members (Figure 31.e, Figure 31.f). To maintain the parent’s privacy, the shared videos cannot be downloaded by the recipients to their personal devices, and the parent can also revoke the access to these videos at any time (DG5).

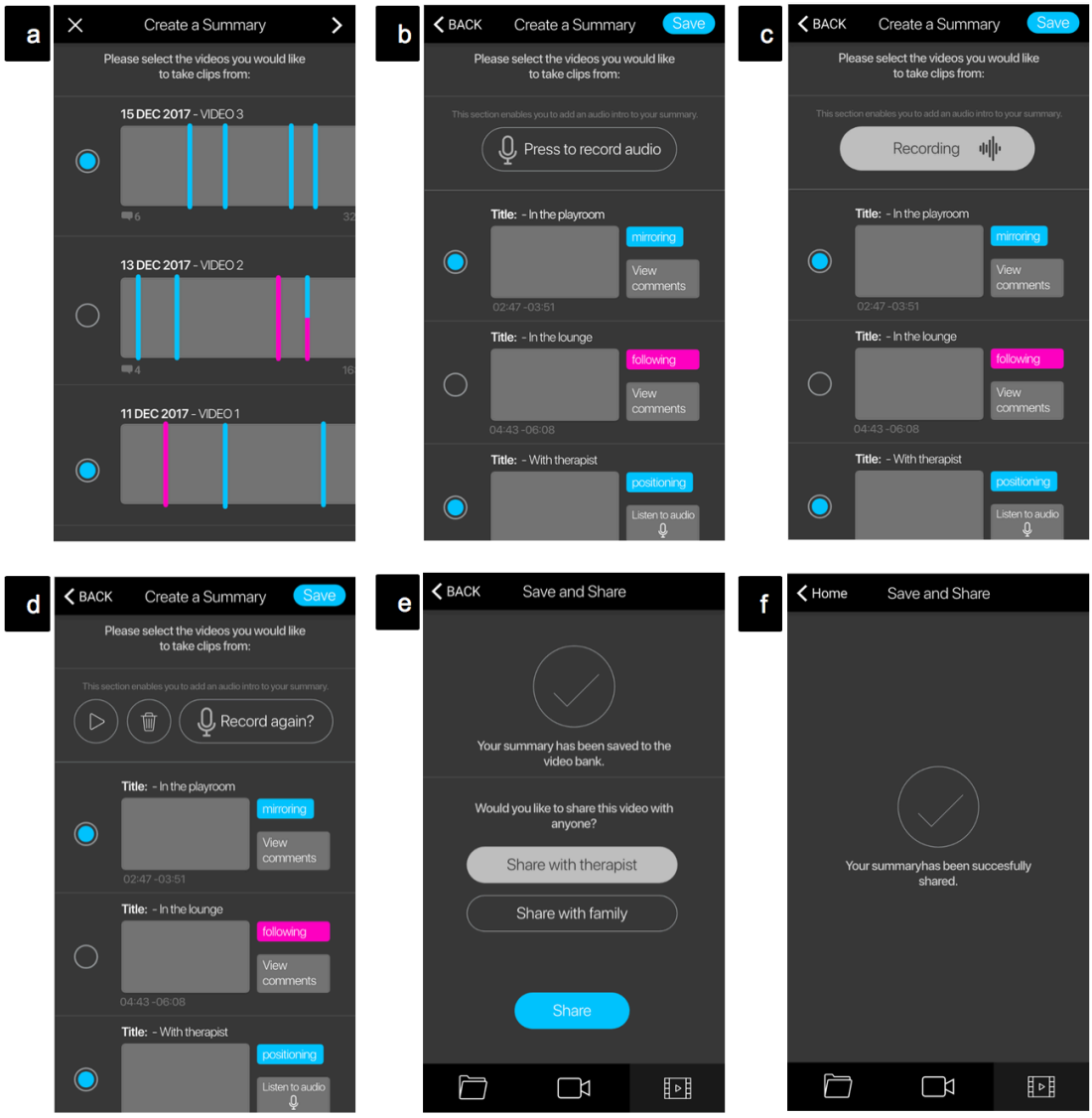


Figure 31. ePACT video sharing scenario

Archiving

The design of ePACT allows the parent to archive and review their video recordings in different ways. Over time the parent will establish a personal library of video recordings showing practices and reflections (called the "Video Bank"), which is fully controlled and managed by the parent alone (DG5). The parent can review the video bank for various reasons, such as remember strategies, or self-motivation (DG4). One of the options provided to review video recordings is to filter them by date (Figure 32.a). ePACT also automatically relates streams of tagged moments (based on tag name or favourites) and categorises them into specific folders (Figure 32.b). When the parent selects a specific strategy folder or the best-moments album, a related list of the tagged moments will be chronologically displayed (Figure 32.c). The parent can also access the relevant annotations and comments by selecting one of these moments (Figure 32.d). The video bank library allows the parent to can access a visual demonstration of the strategies and this becomes their main source of feedback (DG2).

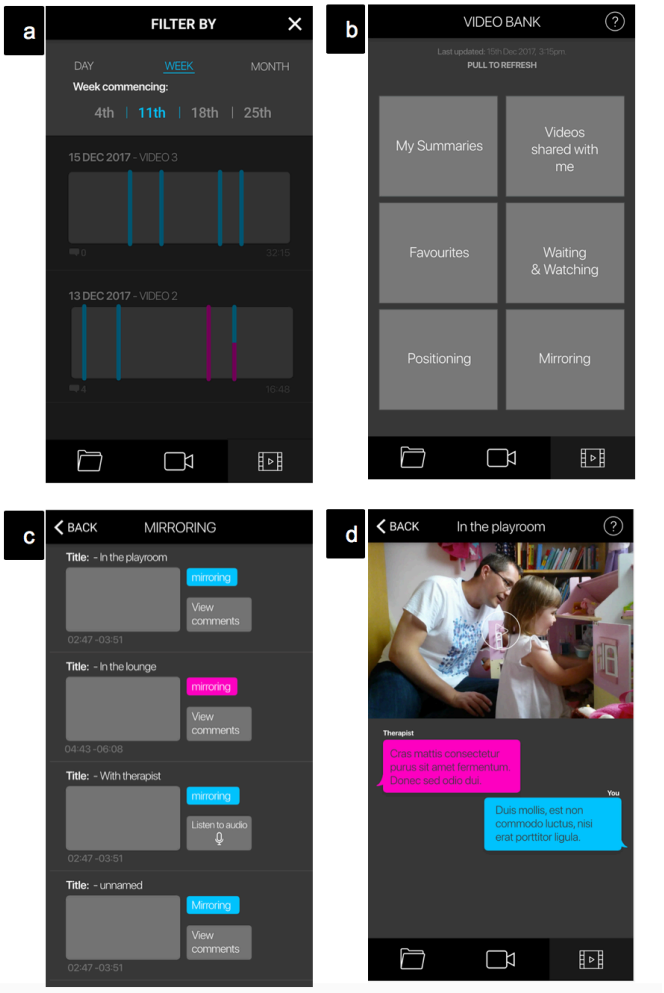


Figure 32. ePACT video archiving scenario

7.5 Phase 3: Study Design

The third design phase was aimed at reviewing and critiquing the design mock-ups and finalising the design decisions. One two-hour joint design workshop at each location (with mother and therapist participants) was conducted to scaffold the design discussion. The Newcastle workshop involved two therapists and two mothers. Although all of the participants agreed to take part in the workshop in advance, one of the Manchester mothers was unable to attend on the day due to unexplained reasons. Thus, the Manchester workshop was held with two therapists and three mothers.

To facilitate the design review process, critique cards were used to guide the participants and allow them to record their review comments (Tomitsch et al. 2018). The critique cards came in three categories (see Figure 33): 1) things they liked about the design (Blue cards), 2) things that were not clear in the design (Yellow cards), 3) new possible scenarios suggested by participants (Pink cards). The participants were advised to use the critique cards to write their comments and focus on the system functionalities (how/why/what) rather than the graphical representations or their personal expertise.

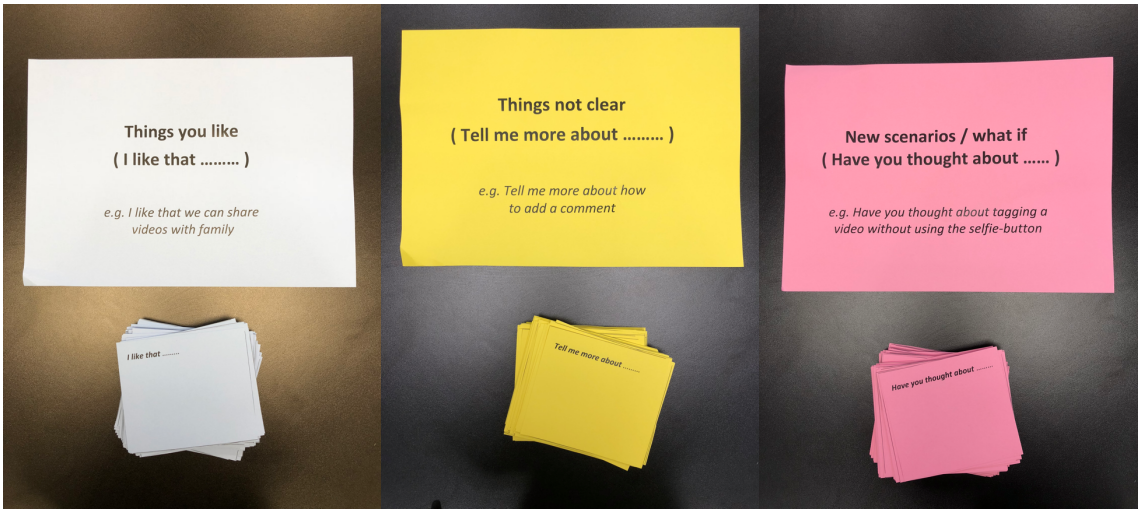


Figure 33. Design critique cards

In the workshops, participants were divided into two group; where the mothers grouped with the therapists. The workshops were structured based on the five main functionalities of the system: capture, annotate, share, review, and archive. For each functionality, participants were asked to navigate through the mock-ups (provided on laptops) and write their comments on the relevant critique cards (see Figure 34). At the end of each task, participants' comments

were discussed, along with other principal functionalities such as storage limitation, security features, and any privacy concerns. The participants were also asked about alternative scenarios, such as the need to edit the video content before sharing, the challenge facing the therapist if they received more than two minutes of video, and the ability to establish group discussions. The discussion outcomes were used to confirm the design consideration to support parent-led video feedback practices.

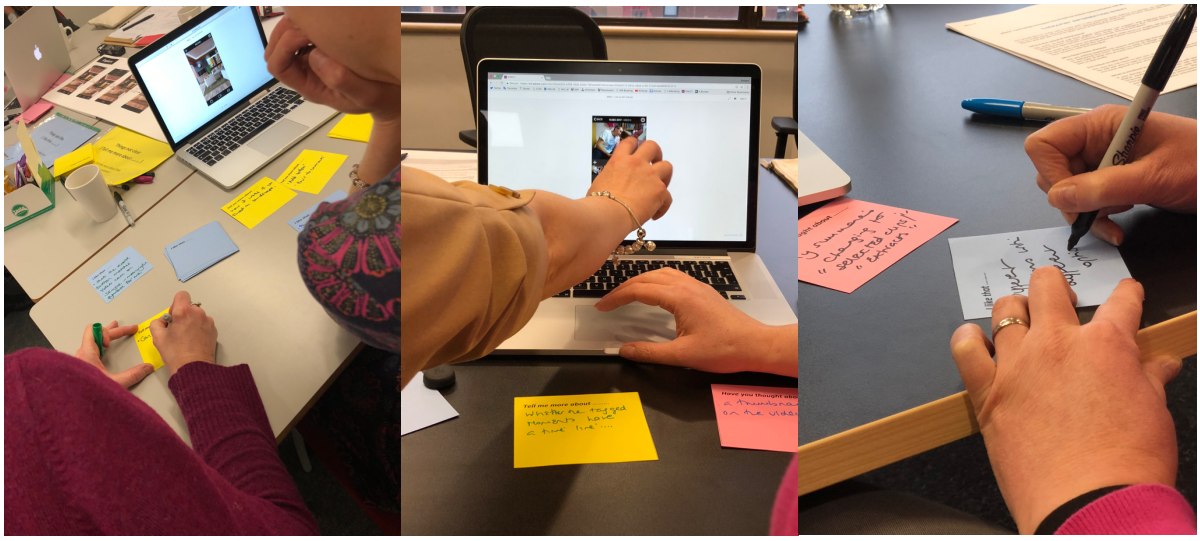


Figure 34. Design critique workshop

7.6 Phase 3: Design Critique Findings

In this section, we describe the main themes resulted from the analysis of discussions held in the critique workshops. Generally, the findings revealed the perceived benefits, potential concerns, and further suggestions of design features.

7.6.1 *Familiar In-Action Moment Capture*

Generally, the mothers and the therapists reported that they found the video recording interface familiar and easy to use. As P04 commented, *"I liked that it is just click through to go and to stop, so it is plain and simple. So, it is nice and straightforward, then, for anybody that is not very good with smartphones or laptops or anything like that."* Although in the design phase 1, the mothers were against the use of an external camera, they liked the idea of having it as second option. For instance, P03 expressed how it could be useful during the therapist visit: *"Like a therapist comes and they have got their own camera, they might want to just add it to your phone."* Even with agreement on the practicality of video capture using a

smartphone, there is a need to resolve the associated challenges to make the capture process less disruptive; such as controlling the phone notifications or calls, and ability to acknowledge recording while ensuring the screen is less attractive for the child. Furthermore, limiting the recording duration to a specific time was suggested, especially for anxious parents, to avoid adding pressure to show their best practices or review a long duration. As T03 remarked, *"The idea is that within that time, you can always find something, and you do not want parents recording and waiting for the perfect moment because we can work with whatever."*

Additionally, with the use of a small Bluetooth button, the mothers believed it would be easier to control the recording remotely without interrupting the play session or the children, nor needing to get the help of other carers. While the start of a play session cannot be predicted, the mothers found it helpful to use the button to start recording whenever the mother-child engaged into the play, without breaking the flow of interaction or recording useless moments with no real interaction. Furthermore, mothers and therapists believed that the use of the button to tag moments while recording would encourage reflection during the play session. The mothers expressed how this would facilitate marking specific interactions that they felt to be important while playing with the child, while the therapists expressed how this would help them to explore the parent's targets for the session. As T01 said, *"It would be really helpful to know what parents are thinking, are they conscious of their goals when they are playing or are they just trying to get a nice play session ... It gives you a bit more of an insight."* However, re-watching the whole recording is an element of PACT practices to enable the discovery of the communication signals that were missed during the play moment; therefore, in-action bookmarking would be useful as a self-prompt for interesting moments to start and expand the reflection. As T01 remarked: *"I liked that it could be all set up before play, so you can have your camera ready and then think, more spontaneously, 'This is a good moment, let's start this recording.' Also, that you tag moments in play, just to give you that memory jog. So, it could just be that moment and then you could go back and expand where it has happened."*

Another scenario was suggested to use the button to mark moments during the visits, so that the mothers will have more visual examples for the home programme, plus the remaining moments from the session for personal reflection due to the limited session time. For the home visits, it was suggested to have two separate tagging buttons, one for the mother and one for the therapist, as P06 explained: *"Possibly both of them tagging. But you cannot see*

the others and the parent always go first and then if you have got any tags that – because often the tags are the same – then if there are any surplus, the therapist can just go, 'Well, actually, I have got a couple of others, that I would like to look at.'"

Finally, the mothers and the therapists suggested to keep the screen unlocked to allow a time delay between setting up the phone and starting the recording; having landscape as the default setting as they do normally; acknowledging the button press in various ways (such as sound or vibration) for different parents' needs; and the ability to personalise the video title based on date and play scenario, but not strategy.

7.6.2 *Flexible and Free-Form Annotation*

The video annotation process was reported to be flexible, with the undefined strategy names and moments-based dialogues. The therapists found the process would facilitate parent-led reflection, as T05 said: *"What I like about this is that it is parent initiated, so it is the parent that is tagging the moment that they think is significant, which I think is great."* The therapists confirmed that the parent-led coaching system is aligned with the PACT principles, as T01 commented: *"The way that we are delivering PACT at the moment, we would definitely be told not to change the parent's words and not to bring them to our strategy and not to make it uniform."* The timeline view with the tagged moments listed was reported useful for quick access to the marked moments, allowing the user to select a moment, watch it, and re-evaluate the interaction and related strategies. For instance, P02 said: *"It was really clear to see what your tag moments were, from the other moments that you have not tagged, so you could just go straight to it. So, you can just click on that blue line because that is the moment. Say, for example, you think, 'Was that mirroring or was that something else?' You can just go back and just re-evaluate it."*

The mothers and the therapists also reported the usefulness of having the option to manage the marked moments, either by deleting or adding more tags, due to the immersive nature of parent-child interaction which might lead to less use of the live video tagging. As P06 commented: *"Some parents might not be interested in tagging as they are going, because they are so involved in the moment. So, actually, they do the work afterwards when they are watching the video and that is when the tagging starts, which also you can do. So, you actually do not use the button at all, apart from to start and stop."*

The mothers and therapists found the process of reviewing and adjusting the duration of marked moments would promote the self-reflection skills of the mothers, as P04 explained: *"Having to analyse where to start and end, you are really, really having to look and think about. So, it is like, 'Why have I chosen to come in there? What is actually happening?' And it might make the parent become even more aware of what it was that began that interaction and what it was that ended it. 'What did I do?' 'Why am I stopping there?' 'Ah, because I said too much.' And, you are actually almost learning something through that editing process."*

Therapists and mothers reported the value of having an undefined strategies list, which would give them the flexibility to establish and personalise the strategy list based on the mother's progress in the programme, so that the strategies added to the system were based on the mother's language and what they had covered in the therapy. It was suggested convenient to record the goals and strategies on the system rather than using the home programme, as T02 explained: *"We liked the idea of strategies practices being in the phone and not on paper at home because then when you are out and about, when your children are at swimming, you can remind yourself because it is really accessible. It is portable, and you can remind yourself."* The mothers added that the strategy list would became easier to follow with visual examples from the sessions, rather than having a structured practices list. As P03 said, *"That is the beauty of it, I think, because I did ABA with my son, and that was very much like you had to follow literally. I would be there with sheets of paper on the floor trying to practise it and that is hard. This is so much easier."* The therapists found it valuable to have the undefined labelling system in order to keep the labelling open to mothers based on what they found interesting in the recording, either to represent a strategy or an activity. As T01 commented, *"I do not think you would think about it in terms of strategy labels... So, it would be good to self-label what is relevant to you, what you felt is important."* Additionally, it was suggested to add a weekly prompt for the strategies for the mothers to focus on, based on the recent strategies that had been added to the system.

Although the mothers and therapists liked the option to audio record their comments instead of writing, they expressed the challenge of recording the comment in the shared places. For example, P03 commented: "*I would always rather write something – particularly if I was on my own, I would feel a bit silly. And it does depend on where you are doing it and things. If*

there are other people around, actually, if you have got your headphones on to listen, because you do not want to have to be speaking to it, do you? You just want to type."

The therapists discussed the importance of having a written record of the coaching dialogues for the therapy reports. As T02 said: *"I suppose, if you were text responding you would have your printout, would not you? But, if it was just audio you would lose that. So, I suppose, I am conscious that we want this to decrease our workload."* The ability to mark tags as favourite was perceived as beneficial to highlight the moments that represented good examples of practice, as a self-reminder of progress, and as a tool for the therapist to prompt the parent when needed. As T05 commented, *"So then they have got a list of their favourites. I suppose, that would be helpful for reminding yourself what progress has been made ... but also as a prompt so that, as a therapist, you kind of say, 'Remember that moment!'".*

7.6.3 *Dialogues, Feedback, and Time Boundaries*

The ability to establish dialogues and integrate the therapists' comments and feedback was valued by the mothers, with the colour coding used to differentiate between the parent and the therapist's comments and tags. One of the risks discussed by the therapists was the possibility of the parents logging all of the unsuccessful interaction moments, but they found this issue resolvable by communicating specific targets for the parents to focus on each time. The therapists also discussed how collaborative agreement through the dialogue can facilitate correcting the parents when they focus on negatives, by pointing them to good moments through the therapist' added tags, as T05 said *"That is why it is good having the tag that you can add, because that is where, as therapists, we might go – 'That was a really lovely moment of shared attention,' but the parent has not seen it. So, you want to draw their focus to that."* Moreover, one of the associated challenges of text communication is the possibility of misinterpretation and the lost elements of face-to-face communication such as facial expressions. As T05 put it, *"It is the same with any text speak, you lose something through the text speak that you get if you have an actual conversation with somebody ... Or, it could be misconstrued, just because it is a comment that is written down."* However, the therapists suggested arranging sessions based on the needs observed through the self-coaching system, such as when there was a risk of written practices being misconstrued. Furthermore, the therapists suggested new ways to annotate and share their feedback by drawing on the video frames; for example, drawing a triadic gaze, mind maps to label possible words to use in a situation, or speech bubbles to verbalise the child's thoughts. As T03 said, *"If you could*

freeze-frame on a still where maybe the parent and child were sharing the gaze or attention with an object, you would draw the triangle, so you could see the three things." The suggested annotation is expected to be more therapist led and used with the visual learners, as they usually do in the actual sessions.

The conversation notification was reported to be easy to notice and made familiar by other applications, but it was suggested to add notifications by moments for more precise identification, not only on the whole video. Additionally, the read receipt was recommended by therapists and mothers, with the ability to disable it when the therapist is out of the working hours. With the possibility of the parent sharing multiple moments reflecting a specific strategy, the therapists reported that they would select the most suitable example to provide their feedback. For example, T02 said, *"You would not want it to be that you had to comment on every tag. I am thinking, like, if triadic gaze is going well, you might get fifteen instances of triadic gaze. You do not have to comment on every single one."*

The therapists expressed their concerns about setting an expectation of a greater level of service with the use of ePACT. As T05 commented: *"PACT is quite an intensive programme, and for the vast majority of NHS therapists, I do not actually know whether they would have time, every time the parent notification comes up, to respond… I think you would have a tricky job, for some parents, managing that expectation of, "I have sent something, so you need to reply," of how often you are going to have the chance to reply."*

Different arrangements were discussed to set a time agreement between the therapists and the mothers to receive feedback. Initially, the therapists suggested having an agreement on the number of videos they could review per week. As T01 commented, *"I think you would have to have an agreed – 'I will be able to watch one of your videos in a week. You pick the one that you want me to review.'"* Likewise, the therapists suggested to arrange for synchronous conversation online when needed rather than spending longer duration exchanging messages offline. Yet, the therapists suggested to limit the duration of the therapists' availability online. As T03 put it: *"If you have a really fantastic mum who sends you a video and wants to really dig into the issues, then you spend your whole week talking about that video, whereas if you say that you are online for half an hour to chat, 'This is your time with me,' it is more boundaried."*

7.6.4 *Moments Collection and Caution when Sharing*

With the ability to share the captured moments with others, the mothers expressed the value of sharing annotated videos with their family or the child's teacher, as well as discussing them with the therapists. For example, P02 said: *"If someone was looking after my child who had not looked after them before, then I would share the video to show them, 'This is the bedtime routine. This is the way he likes this.' Then it is a quick way of – 'Right, there are two minutes, that is how you do it for them' – to sort of get it right. It is just using the app in a different way."* The therapists also found the remote sharing useful for them in order to monitor progress and identify opportunities to encourage and promote the parent's skills, as T02 explained: *"I would like to be able to look at that, because we like to look and see the progress that children have made and actually it is helpful because if parents are having a bit of a down week or something, you could be like – 'Oh, hang on, I looked in your library and look at how far he's come.'"*

Furthermore, the mothers reported that sharing would be easy and practical, either by shortening the video to the best moment or selecting multiple instances of a strategy from different videos. As P04 expressed it: *"Because you might find that you have got a few really good focuses on mirroring and you want to show that a few times to your therapist or to a family member. So, you are grouping what you are working on and showing those short clips. So, you just clicked that circle and then the share icon comes on and you click on that. So, it is nice and straightforward and easy to use. And you can shorten the video in the best moment; you do not have to send the whole part, you just send them really good bits."*

The therapists also confirmed the importance of reviewing a collection of clips from different videos, as this can show the parents' ability to generalise practices. As T02 noted, *"Actually, I find it really helpful if they are from different practice sessions, because then I know that it has happened on different occasions."* However, one mother and one therapist revealed their need for simple and direct sharing of single moments, as T01 said: *"Sometimes I would do the video bit, edit it and do the tags and I would want to share it at the bottom of there. And I cannot imagine going back in and picking out things from more than one place."*

Due to the sensitivity of sharing personal interactions in the real environment, there was a discussion around the importance of access to the whole video. The mothers and therapists insisted on the importance of selecting and sharing specific moments for reflection as this was

considered part of the self-reflection practice. However, the therapists might need to review more interaction beyond the shared moment, either because something happened before or after that moment or in order to provide proper feedback. One of the discussed solutions was to grant the therapist full access to the original video to avoid delaying the feedback, as T04 explained: *"I think it would be nice to always have access to that as the sort of default position, so that when somebody has sent you something interesting that you can immediately look at the bit before, if you feel you want to. Otherwise, it might just delay the feedback."* However, there is the possibility of recording inappropriate or not-relevant content that the mothers might not be willing to share. Thus, it was suggested to allow the parent to block sections of the video while the original video remained accessible when the related moments were shared. As P06 explained, *"If your husband has sworn on the thing or the child starts taking his clothes off, sometimes you do not want to share all that. I suppose, yes, just to have the option to withhold some parts, because there might be some that you would not want them to have the whole access to."*

Finally, additional sharing recommendations were suggested by the mothers and the therapists. Initially, the importance of reviewing and re-watching the summary video before sharing was confirmed by the mothers and the therapists, in order to ensure that the correct moments were selected. The mothers also suggested additional ways of sharing beyond the coaching system, such as selecting moments to share via email or WhatsApp. The therapists reported the need to constrain the sharing to one to two minutes, as in the real PACT protocol practices.

7.6.5 *Video Bank: Progress, Privacy, and Access Constraints*

As discussed earlier, the mothers and therapists were keen not to have any quantitative recording of the strategies practised; thus, the video bank was reported to be useful to archive the moments and empower the mothers with their personal library of practices and achievements. The video listings based on strategy were perceived valuable and easy to access, as the strategies appear as they have been tagged or discussed, rather than being a pre-set list. The therapists discussed how the video bank could also include video examples from the face-to-face sessions. As T02 said*: "We had an idea that the 'Videos shared with me' for the parents, there would be no reason why you could not use the app in the live session. So, the parent got the whole bank of therapy. Because lots of parents ask for all the videos, and it is really difficult getting that data to them because it is so big."*

Although the therapists reported that improvements cannot be noticed per strategy, they confirmed that the overall interaction within a captured moment can reflect progress when compared to earlier videos. For example, T05 explained, *"I think the parents who I have worked with, when they look back they tend to just like going back to the early clips, so rather than looking at specific strategies they tend to just go back to that first session and then: 'Oh my God, what a difference there!'"* The mothers confirmed that they notice progress in different ways and found the video bank listing would be effective for them to compare videos, as P04 remarked: *"You would go back to when you first started and just generally looked at how the interaction was compared to now. It is quite effective!"* Furthermore, the mothers suggested an added flexibility in organising the video bank library, by having the ability to create more categories specified by the parent, and the ability to list the videos based on names or labels.

The therapists believe that the video bank library is more useful for the parents, but should not be fully accessible by the therapists, since it is a tool for parents' self-reflection practices and thus it should be under their control. As T02 said, *"I suppose I see it as more for the parents. Almost like a 'See how well it is going,' because when it is going really well, it just becomes part of your day."* Similarly, the mothers expressed their preference for having more privacy control over their own video library. As P02 said, *"You can always have an option where it is, like, 'for my eyes only' and that would just be for yourself."* Additionally, the mothers believed that sharing meant less control over their personal data, as P01 explained, *"I think we are in an age where you know that if you send something to someone, that is it, it is out there; so if you did not really want anyone to have access to it, you probably would not have sent it in the first place."* Therefore, as a way of providing more privacy control for the parents, the therapists suggested limiting the video access after sharing to a specific duration of time specified by the parent. As T03 remarked, *"Like what happens at the minute with the links we send, once the links expire we lose access to the videos."* However, the therapists discussed their need to keep access to the videos for ten years due to NHS regulations, and their belief that they had got strict guidelines for data protection.

One of the challenges reported was limited phone storage and the need to securely store the video library externally. For example, T02 commented, *"If you wanted to keep the whole bank you would have to have some sort of cloud. The videos could use up a lot of space. Especially if you have got an iPhone where you cannot extend your memory."* The mothers

expressed their interest in storing the data externally to solve limited-capacity issues, as well as to access a backup copy in case the phone was lost. However, the mothers were concerned about the level of data protection and the storage management authority; as P03 said, *"But it depends, who is managing it and what their data like, how much data they have got."* The therapists reported that cloud storage is not always secure.; as T04 mentioned, *"I was just thinking, even things like the clouds and things, often they say they are not secure enough. So, even for those, you are sending them over and it is a video of you and your child, you do not want them to be thinking it could be going anywhere else."*

7.7 Discussion

Technologies for observation and remote coaching often aim to address the limitations of direct observation or therapy delivery, where the therapist still plays a central role of assessment and teaching (Aggarwal et al. 2015; Hayes et al. 2008; Nazneen, Rozga, et al. 2012; Mamykina et al. 2008). But what about empowering the parents with tools to facilitate adoption of therapy programmes and to make them realise their own skills and capabilities, and the importance of their role in early interventions? In designing ePACT, we have identified opportunities for a self-directed coaching tool to enable and support parent-led reflection and knowledge management in indirect-therapy programmes. Empowering the parent leads to enhancing their behaviour, their self-knowledge, and the knowledge of the other caregivers of their child. The findings show that ePACT can contribute to engaging parents in building their own reflection skills and the potentials of technology to facilitate adoption and adaptation of home practices. With this design study, in which parents had had prior experience with video-based reflection, the design activities showed the need to ease the burdens of the current PACT therapy delivery programme. These burdens include data capture, communication, and generalisation of learned knowledge. With the replication of video feedback practices by the parents in their own environment, the parents can improve their reflection skills and reduce their reliance on professional support. Consequently, enhanced parent skills will result in continuous adaptation of therapeutic practices that promote the communication development of their children.

The ePACT study revealed that the parents learn the therapy strategies and the techniques of video reflection during their interaction with the therapist. However, the crucial need is to promote continuous engagement with the therapy practices beyond the therapy coaching

session. Thus, whether or not the parents comprehend the required skills for adoption and reflection, they need an aiding tool to use at home and facilitate maintaining or learning these skills. Through the design of ePACT, we anticipate that use of the technology can impact three different dimensions of analytical, behavioural, and emotional states. Firstly, with the establishment of a parent-led video feedback model, the parents can enhance their analytical and reflection skills, which can result in changing their behaviour and their abilities to generalise practices, compared to the existing reliance on therapy sessions. The parent can independently review their home practices and assess their correctness and the issues surrounding their adoption, compared to their previous practices at home or at a therapy session. Secondly, various levels of support can be achieved through the technology which can impact the parents' emotional state. Below we articulate the outcomes of the co-design study as three design elements of technologies to support parent-led video feedback technology.

7.7.1 *A Dynamic Model of Video-Based Coaching*

The therapeutic knowledge can be accessed through the therapist-parent interaction, but the focus is on changing the parent's behaviour, not only their knowledge; this will lead to better child development (Kretlow et al. 2011; Meadan & Daczewitz 2015). Based on the parents' learning styles and assistance, the participants' experiences showed that the parents can analyse an interaction situation, identify good communication, and replicate these communications. Thus, the technology should focus on providing instruments for home-based practices and not only for remote service delivery. Since the 1940s, video has been used as an element for observation and reflection (Balldin et al. 2018). The PACT protocol showed a successful adaptation of video feedback (Kennedy et al. 2011; Pickles et al. 2016), but only for parent-therapist interaction and guidance. Although the therapy programme follows a specific structure, the design process revealed that self-directed coaching technology is not restricted to the programme structure. Thus, the design direction led to enabling self-reflection based on video recording, resulting in a dynamic model of coaching that is not limited to a therapy protocol.

Initially, an independent model of coaching in ePACT could be established based on selective video archiving, which is used as a tool to allow the parent to continuously adopt the video feedback practices at home. Based on the proven potentials of tele-coaching technology via videoconferencing and capture at home (Suess et al. 2014), the flexible and less formal

communication channel of ePACT extends the independent coaching model and enables various ways of adopting the system. Thus, the design of ePACT introduces various models of communication (including synchronous or asynchronous communication) that can be used in different models of coaching (including peer-to-peer, parent-to-family, and therapist-to-therapist coaching). Moreover, although the focus of the design is limited to the PACT therapy protocol, we do not anticipate that video feedback practices would be different in other therapy programmes for other special needs that use similar video coaching techniques.

7.7.2 *Simplicity Encouraging Generalisation*

Generalisation of learned skills in every interaction with the child is deemed the ultimate goal for the indirect-therapy protocol. Generalisation must be guided not by professionals but by parents, due to their daily interaction and caregiving routines with their children. Therefore, technology must consider socially acceptable techniques to encourage generalisation and adoption of the learned skills, either analysis skills or communication strategies. One of the resulting design sensitivity concerns is simplicity, in order to promote adoption and adaptation of technology. Subsequently, technology simplicity will influence the parent's adherence to self-reflection practice and their generalisation of the learned skills in the various settings of interaction with their child. Additionally, the home-based tools must fit the existing family dynamics of communication and capture without adding burdens to their existing practices, for example by using specialised devices or unfamiliar ways to interact with the technology. Various studies have documented the importance of enabling the assessment with minimum effort or workload (Hayes et al. 2008; Marcu et al. 2012; Hayes et al. 2011).

Throughout the ePACT design process, we revealed simple ways of encouraging reflection that is not limited to professional comments and directions. A simplified version of selective capture is based on the familiar devices used by the parents: their personal smartphones. Selective capture has been widely used in various video-based assessment contexts to facilitate observation and discussion (Nazneen, Rozga, et al. 2012; Hayes et al. 2005; Hayes et al. 2008; Mamykina et al. 2008). To make it easier for the parent to use the selective capture techniques, their personal smartphone is used as a reflective mirror where they can review the recorded videos to see themselves interacting with their child, assess the interaction, and relate it to the knowledge learned in the therapy sessions. The design considered uses video capture and editing as tools to promote the parent's reflection skills.

For instance, when the parent bookmarks moments during their interaction with the child, they initiate the first step of selecting moments for review. Furthermore, with the ability to adjust the marked moment duration, the parent is actively looking at the action that initiated that moment and the action that ended the moment.

As a result, the parent is deeply analysing the interaction situation and assessing their own behaviour as well as the child's behaviour, in order to understand the action trigger. However, for less reflective parents, remote professional guidance with the self-reflection tool may help them to see the potential of interaction observation, using examples of true interactions from the child's environment. Through the parent's reflection on the captured media, they can effectively realise the child's social and communication needs (Marcu et al. 2012), and act accordingly to meet these needs, support the child's development, and understand the value of the sustained adaptation of therapy practices in their everyday routines.

7.7.3 *Avoiding Isolation and Managing Privacy*

Social isolation is identified as one of the major challenges in the caregivers' lives and is exacerbated by the lack of communication channels with professionals and family networks (Schorch et al. 2016; Liu et al. 2011). The existing communication techniques are not as effective as they should be at reducing the feelings of isolation for parents who are already challenged by their children's special needs. Isolation and loneliness can also lead to reduced parent commitment to the therapy practices, subsequently reducing the potential of the early therapy intervention to impact the child's development. Therefore, the self-directed coaching technology should promote collaboration with therapists as well as the existing network of caregivers. With access to the needed level of professional support, the parent can be reassured. The design of ePACT develops a model of interaction where the parents get bits of advice and progress rather than waiting for a professional coaching session. Additionally, emotional support can also be accessed through these channels, either through professional encouragement of repetitive good practices or through capturing and sharing achievements with family and other caregivers. As a result, the ongoing support channel will reduce the therapists' worries about creating a log of all the negative interaction moments, for example those where the parent felt rejected or frustrated.

On the other hand, continuous collaborative support could be associated with time burdens and data protection concerns (Liu et al. 2011; Marcu et al. 2012; Nguyen et al. 2009).

Conversation-based coaching is a deliberate design choice that sets expectations of therapist support, yet there is a need to establish boundaries to avoid overloading the therapists. These boundaries might involve limiting the duration of shared videos, using remote support as a replacement for the remote sessions, or involving experienced parents as an alternative coaching source. Moreover, the data protection concerns were emphasised during the design discussion of video sharing. The discussion captured in this study revealed the need to balance between the therapist's possible need to review a full interaction video, and the parent's concern about recorded content that they might be unwilling or find unsuitable to share with professionals or others. Thus, in parent-led coaching solution, there is a need to provide clear record of what has been shared with whom, while allowing ways to control the video segments sharing.

7.8 Summary

In the ePACT case study, we expanded our contextual exploration to another form of indirect therapy programmes and explored the role of parent-led digital solutions in supporting parents of children with autism for in-home therapy practices. The video feedback and reflection revealed to be an integral part of the PACT therapy protocol; thus, the design process further extended the discussion to integrate self-reflection and alternative techniques for data capture and access. The findings confirmed the importance of designing remote coaching solutions that promote generalisation and maintain the parents' engagement with therapy practices.

The design process of ePACT study shows different methods to engage the mothers of children with autism in the design of digital solutions that fit their needs and balance their needs with the professional therapists' requirements (related to RQ2). In Chapter 6, we provided a contextual exploration of the existing challenges and experiences of indirect therapy programme (related to RQ1). As a response to the contextual exploration and the parents support needs in the context of PACT, this chapter introduced a design of parent-driven self-coaching technology. As a result, we discussed the opportunities for a responsive model of therapist support for home therapy programmes, in which families are more empowered (related to RQ3). The next chapter combines and discusses the design conclusions from both case studies and reflects in the design process of eSALT and ePACT, as an attempt to answer the research questions of this thesis.

Chapter 8. Discussion and Conclusion

8.1 Introduction

This thesis has explored the experiences arising from participation in healthcare and the importance of the role of design process in organising this participation. It has thus investigated how participation has become an integral part of the design process for indirect therapy, which has valued the design contributions from parents as equal to those of the designers and therapists. Beyond this, our research has also proposed a design for a parent-led video coaching system in response to the particular challenges taking place in the context of the home therapy programmes explored throughout the design process.

In this chapter, we reflect on the two eSALT and ePACT case studies in order to combine the final design considerations that inform the design of a responsive model of support for indirect therapy programmes. The chapter then returns to the main research questions introduced in Chapter 1 to summarise the findings and discuss these questions in relation to the two case studies presented throughout this research. After drawing final conclusions and recommendations, we will present insights into the role of design, power relations in healthcare, research in a sensitive area and the organisational challenges within the methodological design process. In the final section, we outline the main contributions of this research along with its limitations and discuss what lies ahead for future work.

8.2 Reflection on the Design of Parent-Driven Coaching Technology

One of the main aims of the research presented throughout this thesis has been to design digital solutions and techniques in response to both the practices of indirect therapy programmes and parents' needs. Regardless of the therapy delivery format, the two case studies (eSALT and ePACT) have highlighted common challenges facing the parents in adopting and adapting the therapy practices within their real environment.

In Chapters 3 and 6, we presented a detailed and descriptive contextual understanding of the nature and issues surrounding home therapy programmes and responded to the first research question of this thesis: "RQ1: *What are the challenges, opportunities and digital solutions*

involved in the real-world context of early therapy interventions and parenting children with disabilities?" We found that the therapy protocols were focused more on introducing therapy techniques and reflections on parent-child interaction; these were captured either in the session by the therapist or prior to the session by the parent. However, less attention was given to how the generalisation of learned therapy practices could be supported in various interaction situations facing the parents in their daily interaction with their children, which might differ from their interaction during the therapy sessions.

Substantial challenges were faced by these parents when implementing therapy practices, including the lack of regular contact with professionals, loss of motivation and engagement, the stress and burden of caring for a child with special needs, managing multidisciplinary professional therapists' visits and re-coaching other caregivers. As a result of the lack of support, parent-delivered therapies may create an overwhelming burden and result in loss of commitment from parents. Indeed, McGoron et al. have reported that dropout is common in parent-training programmes (rates range from 34% to 77%), due to stress, the significant commitment required, and negative perceptions of the programmes (McGoron & Ondersma 2015). Additionally, in order to maintain therapy practices parents revealed their need for more social support channels to facilitate communication and collaboration with and between the professional therapists, nurseries, other carers and their wider social networks. Consequently, it appeared to be the case that the parents needed more support rather than further sessions of therapy. Here, the types of support ranges from the informational (e.g. therapy guidance) and emotional (e.g. trust and care), to the tangible (e.g. caregiving assistance).

Our thesis hence draws upon the two case studies in order to identify opportunities for designed technologies to play important roles in supporting early therapy programmes, as presented in Chapters 4, 5, and 7. Remote video coaching technology has been introduced intp the context of indirect therapy programmes, although we have not been the first to utilise video capture and remote support for therapy services as remote video communication solutions have been employed as a means for therapy session delivery, either for direct coaching of patients (Ulgado et al. 2013; Mamykina et al. 2008; Owen et al. 2004) or caregiver coaching (Liu et al. 2011; Schorch et al. 2016; Kientz & Abowd 2009; Marcu et al. 2012). Furthermore, a range of data collection and reflection tools have been designed for development tracking at home (Kientz, Arriaga, et al. 2007; Kientz & Abowd 2009; Hayes et

al. 2011), for behavioural assessment in professional environments (Hayes et al. 2008; Kientz, Hayes, et al. 2007), or as health monitoring solutions (Mamykina et al. 2008; Nazneen, Rozga, et al. 2012).

However, the design of a parent-driven coaching solution represents a new contribution in terms of the manner in which it is configured in response to the particular challenges of home therapy programmes identified in the contextual exploration; these challenges include the lack of regular contact with professionals, the need for communicating the implementation of practices and the need for continuity of support. Throughout this thesis, we have identified the values and considerations for designing a digital solution for the indirect therapy responding to the real context beyond therapy sessions, that addressed the third research question: "RQ3: *What is the benefit of involving parents in the design process of coaching technologies and how can this inform future healthcare models to support early speech and language therapy?*".

We have found that there are two main aspects to be considered when designing technologies to support home therapy programmes. Firstly, the technical aspects in connection to the required level of therapy protocol representation through technology and associated information management techniques. Secondly, the social aspects relating to the different support channels have required commitment to be maintained and frustration avoided when the parents perform the practices by themselves.

The case studies have informed the design of a responsive model of support for indirect therapy protocols which combines two elements: data collection to allow the parents to capture rich video records of their interaction with their children, and data sharing to allow the parents to discuss these records with the professional therapists and other caregivers. Based on the field deployment of eSALT and the design critiques of ePACT, we have thus combined the design values and implications that have been found to be most beneficial within the context of supporting the parent-delivered therapy programmes. Each of these considerations is reviewed and described in turn below.

Organic and blending into family dynamics: Our exploration of the contextual dimensions demonstrated the overwhelming nature of the parents' responsibilities for caregiving, learning and sharing their learned experiences within children's caregiving network. Furthermore, this

research has revealed that in these cases, parents strive to coordinate and communicate not only the knowledge learned but their concerns and achievements by using multiple applications on their smartphones. Thus, any designed technology should not add to the parents' burdens and should blend into their existing practices. As an alternative to the most often designed solutions in various contexts of support at home (Kientz et al. 2009; Mamykina et al. 2008; Hayes et al. 2014), we have proposed the use of personal smartphones to access the needed support, rather than using external devices for data capture and sharing. Through use of portable devices that are widely available, we can then build on the existing parent practices to access support in a less distributed manner, using a digital solution that is designed to address their needs. Consequently, the parents will be able to use these solutions anywhere and at anytime to capture their interactions with their children promptly both to access support at their leisure and to reflect and share their experiences with others. By building on the parents' past experiences with technology, the hope is that easier adoption and acceptance will be ensured (Hayes et al. 2007).

Informal and loosely coupled with therapy protocol: Throughout both case studies, we noted that the coaching techniques used by therapists were less structured, based instead on conversations and continuous dialogue. Regardless of the therapy protocol, the parents were unaware of the overall structure of the therapy programme; this reduced their stress and helped to manage their higher expectations for their children's development. Even with a structured therapy protocol such as PACT, the therapy practices were not predefined but instead planned by the therapists based on the parents' progress, the condition of the child and their current development stage. It was therefore deemed unnecessary to represent the actual strategies and stages of therapy which might result in increased pressure and anxiety for the parents, as they might not be applicable to the conditions of the individual children. We propose that remote support technology can replicate the existing coaching techniques by allowing informal and continuous dialogues to be established based on the shared data, while maintaining the seamlessness of therapy protocol reflected in real practices. As a result, parents can engage more easily in remote coaching dialogues with minimal effort needed to understand while map strategies and stages to the shared interaction data.

Empowering the main caregiver's role: As discussed in Chapter 1, the parent plays a vital role in indirect therapy programmes due to their day-to-day interactions with the child, their knowledge of the child's behaviour and natural environment, and their self-conception as a

care expert to coach and communicate updates with the professional team and the various caregivers. Thus, when designing technology to support the parent in the indirect therapy context, it is important to consider the need to strengthen and reinforce the significant role that parents play in these programmes, so empowering them with the tools that facilitate coordination and collaboration with their social and professional networks. We found in Chapter 5 that empowering parents with a self-led tool initiated by parents has resulted in a better commitment to therapy practices. The benefits resulting here may include the parents feeling more comfortable and able to engage continuously with therapists, so finding support easier to access while being able to manage the information flow within their caregiving network using the self-directed technology. Furthermore, in this thesis and previous studies (Hinojosa 1990; Hinojosa & Anderson 1991), the main caregivers are often the mothers, who are coached individually according to their current parent-child interaction. However, the same empowerment principle is applicable to any of the main caregivers; to the mother, father or any other relatives involved in the caregiving network around the child. As we found in Chapter 3 and 6, communication challenges evolve beyond parent-therapist interaction, while inter-family collaboration and dissemination is an extension to the caregiving network that is not widely acknowledged in the design for therapy services. Therefore, it is important to consider inter-family communication in the design of these tools in order to support and facilitate the main caregiver's role further.

Self-collected data in the natural environment: Previous works have discussed the challenges of direct observation and the value of reflection on real interactions happening in the natural environment for effective professional assessment (Kazdin 1977; Kazdin 1982; Hayes et al. 2008; Nazneen, Rozga, et al. 2012). These challenges include a lack of real context, the invalidity of interaction with the observer present and the scarcity of the sample data captured for observation. Collecting data from the real environment can eliminate these challenges, being that 1) more natural interaction and context can be captured in various play situations and at different times, and 2) less artificial interaction can be observed without the presence of professionals who might affect the parent-child behaviour. The existing practices presented in this research have demonstrated the use of video recording by the parents to communicate their concerns, to coach and to access support. Moreover, the videos have allowed the therapists to observe parent-child behaviours and use them as a basis to personalise coaching techniques and plans. Two different, selective data-capture techniques were proposed in Chapter 4 and 7, in response to the contextual needs of each of the case studies. In eSALT,

retrospective capture was proposed to enable the recording of concrete and past interaction moments for reflection on specific behaviours without consuming the therapists' time with long recorded moments. In ePACT, selective and in-action moments tagging was proposed to enable more self-reflection, selective archiving and sharing. Moreover, we have proposed that selective archiving can produce natural interactions for observation by concealing the capture technology in the real interactive environment and allowing on-demand capture and annotation via remote control. In addition, vibrotactile alerts can be employed instead of auditory or visual alerts; these have proven their effectiveness in reducing distractions and ensuring realistic data capture (Prewett et al. 2012).

Enabling knowledge, coordination, and social support: We have noted the various forms of support required in the context of parent-delivered therapy. These include information support from professionals and expert relatives, social and emotional support from the therapists and family members, and coordination support for knowledge and experience sharing with the professional caregiving team as well as family members. In this respect, we recognise the need to establish various support channels in the designed solution with the professional and social network of the parent. These communication channels can facilitate parents' access to guidance, feedback, encouragement and reassurance to remain engaged with the therapy programme. In addition, these channels can reduce the time and effort required to communicate and coach other caregivers by allowing the parent to share their learned practices, while providing child development updates with multiple caregivers based on visual demonstrations. This approach has been noted to be beneficial, especially in shifting burdens of communication and support while allowing the parent to work more effectively on ensuring adoption and adaption of therapy strategies in everyday interaction and with all the children's communication partners. Furthermore, the technology involved here might also support asynchronous (when the receiver is offline) and synchronous (when the receiver is online) communication models, based on the receiver's availability when the sharing and conversation are established by the parent.

Maintaining control and privacy: One of the issues associated with personal data capture and sharing is the ability to own and control the data. Perceptions about data control and privacy can be crucial to the acceptability and adoption of data capture and sharing technologies (Hayes & Truong 2009). Throughout the contextual exploration and field deployment, we have also noted that parents might encounter tension with third parties presented within the

interaction environments and with the behaviour of the parent or the child that they have deemed unsuitable to share with others. Parents' concerns can be alleviated through their control of the capture and sharing, along with their awareness of how data is securely stored in their personal devices or central storage. When approaching the design of the proposed solutions (KeepCam and ePACT), we also suggested the use of various techniques wherein the parents themselves can control what data is shared with whom (either by sharing small segments of specific interaction moments or by removing specific frames from the video which they are unwilling to share). Moreover, the parents involved can keep controlling the data even after sharing it, being that the designed technology can prevent the shared media being exported to external storage or to enable the parents from withdraw data access, thus granting data access and control to the parents to maintain privacy and avoid disempowerment. Previous studies have also discussed the importance of shifting control of the organisation data to the users in order to enable cooperation and assure data accuracy (Whitley 2009; Bowyer et al. 2018). Therefore, we echo the need for creating safe data storage spaces that exists outside the healthcare organisation where the data access and sharing is under the parents' control.

Sustainability and long-term adoption: The indirect therapy programmes studied were aimed at promoting generalisations and support self-reflection, while maintaining the parents' motivation in recurring adoption of the learned strategies. Previous research has shown that it is not the amount of therapy that improves parent-child progress, but rather the repetition and generalisation of practices (Hinojosa 1990; Hinojosa & Anderson 1991). As we found in Chapter 6, intensive learning and understanding of the role and strategies of indirect therapy are realised at the beginning of a programme of therapy. Consequently, the parents start to recognise their reflective thinking abilities and the benefits of video feedback and guidance to review their interactions and plan their actions accordingly. However, the professional support is not guaranteed to be maintained beyond the therapy programme to provide guidance and feedback. We thus propose that the designed technology should consider techniques to enable self-reflection and continuous engagement with home therapy programmes. These techniques might include 1) designing video review tools to enable reflections such as in-action tagging or adjustment of the specific interaction timeframe, 2) accessing support not only from therapists but also from a community of experienced peers, 3) collecting personal examples of successful adoption of specific therapy protocols, and 4)

archiving successful parent-child communication moments while automating their reviews (e.g. as annual flashbacks) for encouragement.

Monitoring and resourcing: As discussed in Chapter 1, the current organisation of therapy services cannot accommodate frequent therapy visits due to high demand that outnumbers the therapists available to deliver these sessions (Gascoigne 2012). However, as we have noted throughout this research, the need for more support does not mean the need for more visits in the context of home therapy programmes. In fact, the parents needed more support to adapt the therapy strategies in different interaction situations and to maintain their motivation and commitment. We have proposed instead that a parent-led remote video-coaching solution be used to address this challenge by facilitating remote monitoring of home practice based on sharing video segments and without the expense of conducting a follow-up home visit. Moreover, the ongoing remote support would facilitate the planning of short-term goals and extend progressively to the next goals, where the therapists would establish a comprehensive perception of parent-child interaction in the natural environment. This continuous support will open up new opportunities for therapists to monitor the progress between the home visits and coordinate additional visits when needed. Opportunities for monitoring and support between visits were missing in the previous therapeutic coaching solutions (Gardner et al. 2015; Keck & Doarn 2014). However, one question that remains is whether the therapists' workload will allow the delivery of remote support and coordination with the parents. As discussed in Chapters 4 and 6, therapists have proposed that remote support can replace home visits when there is no progress identified and thus no need to conduct clinical assessment. Moreover, coordination of the therapists' expected response time frame can reduce the expectation of prompt responses imposed by remote coaching technology.

In conclusion, by integrating the design values and considerations presented in this section into a parent-led video coaching system, a *self-organised coaching environment* can be established where the parents are able to access tools and techniques to support their role in the indirect therapy programmes. As a result, parents will be further empowered and receive additional support to foster greater adherence to therapy practices at home. With continuous asynchronous video-based support, a greater commitment to practices might be achieved and motivation can be maintained between the therapist's visits, as revealed in Chapter 5.

Indeed, the mobile video coaching tools have been used as an external driver for continuous engagement with therapy programmes and facilitated social support. Previous coaching solutions have focused on clinical practices and delivering the needed therapy knowledge (Aggarwal et al. 2015; Ingersoll et al. 2016; Vismara et al. 2012). However, in this parent-led coaching solution, we consider the additional factors that surrounds and affects the indirect therapy practices which include parents' needs, various communication and cooperation channels, family reality and the wider support network.

Consequently, an improved relational healthcare model might now be introduced, in which 1) the parents realise and actively practice their central role in the parent-delivered therapy programmes, and 2) the therapists access naturalistic parent-child interaction and surrounding issues to plan individual therapy techniques based on perceived behaviours and the parents' learning and reflection abilities. Finally, the video coaching intervention proposed in this research is designed to be used in therapy for children with speech and language delay due to CP or autism. However, due to the flexibility of the design and its loose coupling with the therapy protocol, the designed technology also has the potential to be used widely in indirect therapy programmes for other early therapy programmes (such as occupational therapies or rehabilitation therapies) or to coach other caregivers (such as learning support assistants).

Finally, the parent-led coaching solution is designed to fit the parents' and therapists' needs to provide the required level of support and improve the therapists understanding of the naturalistic parent-child interaction which can impact positively on the therapy programmes (as discussed in Chapter 4 and 6). Nonetheless, the resulting sociotechnical design is one of the complex domains due to the associated requirements of a cultural and social change in the healthcare infrastructure (Baxter & Sommerville 2011; Bowen et al. 2013). The influence of new mechanisms for therapy and data handling techniques can influence information governance and organisational structure positively.

In these respects, there is a tension between what the parents and therapists need, and what is currently possible through the healthcare system. Several studies have discussed the complexity of healthcare service context, along with the growing recognition of the importance of building collaboration between the service providers and receivers, alongside the significant role of design to improve the healthcare services based on real experiences (Bowen et al. 2013; Gustavsson et al. 2015; Gustavsson 2014; Årsand & Demiris 2008;

Baxter & Sommerville 2011; Sangiorgi 2011; Donetto et al. 2015). However, such interventions can result in sociotechnical challenges within the healthcare setting which are slow to change and not yet fully realised.

We would conclude then that having designed parent-led digital solution to overcome the challenges of indirect therapy programmes, the sociotechnical structure in healthcare is still required to change to make it work. Previous studies have suggested the need to promote the awareness and increase the engagement of the healthcare decision makers in the change process (Baxter & Sommerville 2011; Sangiorgi 2011). We hence echo the need for adjusting the current healthcare sociotechnical structure and the organisational polices in order to create spaces for these changes to be realised with a potential to satisfy therapists and parents needs and improving the early therapy model as seen throughout this thesis. Additionally, within the indirect therapy context parents acted as therapists, parents need to be more recognised as one of the stakeholders involved in decision-making within the healthcare services structures to improve the services they receive.

8.3 Reflection on the Design Process for Indirect Therapy

The design-centred methodology presented in this research has sought to facilitate the contextual conception and introduction of a coaching technology design in response to an evolved understanding of therapeutic coaching needs, not only for speech therapists but for parents with special needs children. To this end, particular attention has been given to the central role the participants (i.e. parents and therapists) played in the design process and how the design and the relevant co-design activities should respond to their practices and experiences. This approach relates to the second research question proposed in this research: "RQ2: *How can the parents of children with disabilities receiving early speech and language therapy inform the design of digital technologies that support parent-delivered therapy?*"

Involving the parents of preschool children with disability and healthcare professionals presents several challenges already outlined in the literature and throughout our contextual exploration (as shown in Chapter 2, 3 and 6). For instance, these challenges underline that both therapists and parents are not expert in design, have limited time due to their work load and/or caregiving responsibilities. They also highlight that children with disabilities demand

care, while some parents are still in the coping stage and their therapists have a restrictive focus on technical solutions for clinical practices.

Previous attempts at design work in the parent-delivered therapy have emerged from clinical perspectives or have focused on self-directed tools designed for the parents to access knowledge (Aggarwal et al. 2015; Nazneen, Boujarwah, et al. 2012; Hwang et al. 2014; Tse et al. 2015). Regardless of the positive outcomes of design processes in these studies, we still need further understanding of the opportunities and methods to co-design with the parents of children with disabilities in the early therapy context. Given the importance of the parents' role in the indirect therapy programmes, we would hence argue the need to engage parents equally as therapists in the design process, so creating balanced perspectives in the design of digital solutions.

To this end, we have developed the design processes and activities for this complex setting to mitigate the contextual challenges, fulfil the participants' needs and engage them in the design process of digital tools to support their therapeutic needs. Various techniques have thus been used to engage the participants in the design process, from understanding their real life and commitments to thinking and carefully crafting activities in response to the participants and study context.

In one possible approach, for example, we started with individual or parents-centric contextual inquiries and observations to discuss personal experiences or critiques to therapy programmes. After creating these common and safe spaces for reflections, we then scaffolded the design discussions in group sessions (i.e. joint with other parents or parents and therapists) as the parents realise their personal expertise and had a sense of ownership to drive the design discussions. Finally, we examined initial design thoughts using new methods by re-appropriating existing tools (e.g. WhatsApp - Chapter 4) or crafting context specific activities (e.g. video annotation boards – Chapter 6). Through this design process, we were able to expose personal experiences and opinions on healthcare services, as well as authenticating the results and design outcomes based on the filed deployment or critique sessions.

In the following sections of this chapter, we will draw upon the two case studies in order to reflect on the role of design and power relations in healthcare for indirect therapy programmes. In this regard, four main reflections have been introduced based on our

experience of conducting design research with parents of children with special needs and healthcare partners from the NHS or healthcare research centres.

8.3.1 *Co-designing with Parents and Therapists*

This PhD research has aimed to synthesise and build upon real experiences in early therapy programmes to discover contextual knowledge, identify design opportunities and co-design sociotechnical solutions and healthcare models for and with groups of parents and therapists. Throughout this dissertation, we have emphasised the essential role of the design process in the research methodology (Bardzell et al. 2015; Yardley 2000; Gaver 2012).

We have also produced and reconfigured insightful and hopefully useful methods in response to the contextual practices. We hence recommend that this design research be employed to enable participants to engage actively in the process, in order that they be perceived as innovators can suggest solutions or share their concerns without risking the health services that they receive or provide.

Moreover, in working towards more participatory engagement in the design process, we demand that the designers become facilitators throughout the process in order that we, as researchers, provide tools to enable the participants' team to step up into the role of designers – this has been echoed by previous studies (Spinuzzi 2005; Vines et al. 2013; Hayes 2011). Here, the design process helped insofar as it enabled us to express our lack of experience with the context and encourage the mothers and therapists to play the role of experts. As a result, the participants have introduced in-depth insights and contextual explanations based on their experiences with the home therapy programmes.

Moreover, throughout both case studies we noticed a high level of enthusiasm and engagement from the participants (both therapists and mothers) towards the configuration of solutions impacting upon their quality of life and the service delivery model. We would suggest that this phenomenon has resulted from working on an important issue concerning the mothers of special needs children. As discussed in Chapters 3 and 6, most of the mothers who participated in this research have dedicated their lives to caregiving and supporting their children's development.

However, no incentives were provided to mothers except the ultimate goal of designing a digital solution that would help them to collaborate and coordinate their caregiving responsibilities. In addition, we noted that original insights were gained by the mothers who valued the therapy's impact. However, external factors affected some of the mothers' engagement with the research (e.g. relatives' opinions) or with specific methods used (e.g. personal capabilities for critical reflection and self-esteem). As for the therapists, we would propose that their engagement resulted from their organisational role as clinical research teams and the partnership has been established with a common goal of improving the service delivery model.

Both eSALT and ePACT have attempted to conduct a bottom-up approach to the design process of parent-led coaching technology, starting with a focus on understanding the needs, context, and services provided with the stakeholders involved. Consequently, an in-depth contextual comprehension of the domain was constructed so that we, as designers, can both empathise with and define the significant issues affecting the real practices, before coming up with design solutions (Gaver 2012; Bardzell et al. 2015).

We recommend that the depth of contextual exploration be decided based on the needs and the aim of the design research and context. For instance, in Chapter 3, a comprehensive and individual contextual investigation was conducted for the eSALT case study in the name of discovering the challenges facing the parents as a result of the lack of therapy services provided. However, in Chapter 6, an individual contextual exploration was deemed an unnecessary step backwards for the ePACT case study, being that the participants were already engaged in a pragmatic therapy protocol. We thus focused on reflecting and exploring the individual experiences with the PACT protocol instead of generic investigation.

We have also adopted a qualitative triangulation approach throughout the design processes realised in this thesis (Yardley 2000). Hence, in each phase of the design process, we have applied multiple qualitative investigation methods and data collected from various sources (i.e. therapists and mothers). These methods have included observations, interviews, design workshops, focus group, video capture and design critique sessions. The individual observations that took place in visits to the mothers' homes proved to be a methodological choice for the contextual inquiry. Yet these were observations challenged by the child's presence and distraction, which limited our investigation activities. While the group co-design

workshops were organised to allow collaborative design decisions, arranging these workshops proved to be a challenging experience due to the associated travel required from the participants' home cities to a central workshop location.

Design workshops were either arranged separately (i.e. sessions for the mothers' group and separate sessions for the therapists' group, as presented in Chapters 4 and 6), or jointly (i.e. mothers and therapists grouped together in a single session, as presented in Chapter 7). These organisational decisions were then based on the aim of the design workshop (i.e. when the focus was only on the design decisions and not critiquing contextual experiences) and the perceived possibilities of creating a balanced collaboration between therapists and mothers. The joint arrangement was planned within the co-design phase of the ePACT case study in relation to the mothers' previous experiences of working within the PACT research cohort and their collaboration with professional therapists.

As a consequence, we were able to note that the joint workshop resulted in innovative discussions and live therapist-mother coaching was observed during these design sessions. For instance, some mothers sought explanations from the therapists about the rationale behind the therapy protocol and techniques in order to brainstorm appropriate design ideas. Therefore, we have observed the value of joint sessions with multiple stakeholders to combine and exchange multiple points of view on the design decisions between the participants.

At the same time, we believe it valuable to confirm that this joint arrangement decision should be taken carefully in order to avoid imposing barriers on the discussions owing to professional therapists' presence, as they might be perceived by some mothers as experts in the design process. In addition, as echoed in previous research (Hayes 2011; Gaver 2012; Bardzell et al. 2015), the designer's role as facilitator is a complex task that requires understanding of individuals' dynamics, group management skills and adaptability.

Moreover, specific design activities have been developed for the co-design sessions in order to establish concrete discussions, provoking innovation and ideation; examples included the design option cards shown in Chapter 7, or the personas and scenarios discussed in Chapter 4. By placing an emphasis on the exploration and design process, we have also innovated design methods to investigate the individual needs and abilities in this therapeutic design context. For example, we re-appropriated existing applications (Chapter 4) and designed video reflection

boards (Chapter 6) as an initial step to examine the practicality of design ideas and explore the participants' abilities, along with the challenges encountered.

Design mock-ups inevitably generate concrete discussions about the required elements of data capture for self-reflection and access to social support. Prototypes were recognised as useful means for exploring and testing design options for digital solutions (Floyd 1984; Lim et al. 2006; Houde & Hill 1997). For KeepCam, we designed a low-fidelity mock-up to test the broad concepts of communication, collaboration and selective data capture (as presented in Chapter 4). Conversely, in the ePACT case we aimed to investigate the necessity of embodying the therapy protocol in the coaching technology. We thus designed a high-fidelity mock-up to examine the detailed process of annotation, tagging, editing and commenting (as presented in Chapter 7). However, a high-fidelity prototype proves challenging for critical discussions as the design interface is quite close to the final product (Floyd 1984; Houde & Hill 1997). Therefore, in order to overcome this challenge, we provided the participants with critique cards to encourage critical reflection, presenting the mock-ups using laptops instead of smartphones and ensuring that the design interfaces were not fully functional.

The various methods and design activities adopted in the two case studies provided a unified language to communicate ideas between mothers, therapists and ourselves; in addition, as they served to promote the participants' collaboration, which led to greater creativity and sped up the design process. We found that the process of research through qualitative design methods facilitated developing analytical and in-depth insights, so informing our understanding of therapeutic coaching needs, while building a deep and rich narrative of the context of indirect therapy which can then be used to produce original solutions.

8.3.2 *Working through and with emotions*

It is important to note that this research has surveyed a sensitive and challenging area of parenting and pre-school children with cerebral palsy and autism. At this early stage of children's development, the mothers in question had either received or were still waiting for their children's diagnoses. Hence, in working with emotionally and socially vulnerable mothers who are still learning to cope with the reality of their children's condition, the nature and context of this research led to a range of positive and negative emotions that impacted upon the mothers and the researcher. During the initial contextual inquiries which took place through the individual observational visits to the mothers' homes in the ePACT study

introduced in Chapter 3, we were able to confirm that all the mothers shared their parenting concerns, emotions and struggles openly with us.

We also found that, for some of the mothers, these visits were experienced as self-relief. Emotional eruptions took place in which some mothers cried while sharing their overwhelming caregiving experiences, frustration, anxiety and stress. Although we had been trying to avoid discussing sensitive topics, the mothers strived to discuss and share their emotions during these sessions. For instance, the mothers explained that their emotions resulted from being able to meet someone with whom they could talk about the challenges that they encountered.

As researchers, we have had to maintain professional boundaries (Dantec & Edwards 2008) while suggesting and referring the mothers to the appropriate support services. Consequently, in working within this sensitive area, we experienced frustration and sadness which resulted in establishing a deep empathetic relationship with the research domain. We have been left with overwhelming emotional burdens, yet these burdens were alleviated in the debrief meeting conducted with the supervisor to discuss the resulting outcomes.

The observational methods and established relationships hence proved productive and enabled us to understand and design for the felt and holistic experiences of the participants. However, whilst we have focused our attention on the design process, we have also had a duty of care toward ourselves. In this sense, we consider the emotional work that we have experienced to be a result of the act of immersing and empathising with the participants as often advocated as a crucial element of HCI engagement in sensitive areas (P. Wright & McCarthy 2010; Wright & McCarthy 2008; Dickson-Swift et al. 2009).

It has then been vital to acknowledge these emotional challenges in HCI practices by providing appropriate support strategies for training and reflection. Dedicated pre-study training can be conducted with the researcher in order to understand what to do with the felt experiences and how to maintain professional boundaries. In addition, a post-study reflection must be employed to relieve any emotional burdens faced by the researcher and to allow them to access support. Similar strategies have been suggested in other professions, where emotional work is considered as a fundamental skill instead of a negative experience resulting from working in this area (Buunk et al. 1994; Mann 2004; Hayes 2012; Ruch 2005).

Furthermore, we have realised that working in this sensitive research area requires designing approaches and methods that consider the challenges of the participants' involvement in the design process and the associated stigma risk. Individual sessions were chosen with the mothers (i.e. instead of group sessions or joint sessions with therapists) when the discussions involved sharing mothers' personal experiences with their children or expressing their opinions about the existing healthcare services that they have received.

In addition, the design personas and scenarios presented in Chapter 4 were built based on the collective and anonymised practices resulting from the observed experiences of both the mothers and the therapists in the previous design phase. As a consequence, we have paid significant attention to ensuring that both the participants and the scenarios could not be related to a particular person in order to avoid creating any emotional barrier to their engagement with the design activity. Moreover, although we collected real video samples from the mothers to be used in the video feedback activity of the design workshop presented in Chapter 7, we organised the activity to ensure that their personal recordings would not be used in their session. However, the mothers reviewed sample videos shared by the mothers who participated in different sessions. This arrangement provided the participants with the means to reflect on the video recordings of "unknown" mothers rather than being stigmatised or exposed to judgmental challenge while reviewing their personal parent-child recordings with a group of participants.

Not only did this mode of organisation challenge some mothers to reflect on child conditions that were different from their personal experiences, but it helped us to realise the obstacles to peer-to-peer support in this context. We conclude that preparing for and working with emotion is an integral part of research in this sensitive domain, which needs to be acknowledged by careful planning and sensitive awareness of the characteristics of the particular context (Light & Akama 2012).

8.3.3 *Power Relations and the Impact of Partnership*

In this thesis we establish partnerships with research clinicians from the Institute of Health and Society (in the eSALT case study) and from the PACT therapy research team (in the ePACT case study). We acknowledge that these partnerships have been beneficial through the design process to explore and understand the quality of design in the healthcare systems. Hence, establishing relationships with community partners has been increasingly recognised

to provide long-term value to society and promote sustainable change (Hayes 2011; Palen 2010; Foth & Axup 2006).

Throughout this research, we recognised that it is not enough to produce a responsive design, but instead to provide a design that speaks to professional perspectives and concerns. The role of collaborative partners has hence been significant in the way that they have facilitated access to resources and the overall organisational structure of the healthcare systems of early therapy programmes. However, the challenges posed by power relations have proven inevitable between our role as an HCI designer and those of clinical partners (Karnieli-Miller et al. 2008; Hayes 2011) to the extent that all such participants have influenced or challenged the design process.

The need to value the design process and decisions has not yet been well-perceived in the clinical research. Earlier in this research, we noticed multiple situations where the clinical partners tried to impose their design ideas rather than allowing spaces for participants' viewpoints. Instead, we have attempted to address the power issue of clinical partners by showing evidence and in-depth insights that resulted from the design process without compromising design decisions. Adopting a collaborative approach and securing partners' engagement throughout the design process has resulted in trusting relationships and comprehension of the role of research through design. Consequently, the clinical partners have realised how and where the design fits into this process. Indeed, the clinicians' realisation of the value of research through design has progressed as we moved through the design phases.

Moreover, in the initial research stage, our research collaborators have acted as "gatekeepers" and significantly facilitated recruitment of participants from their existing networks in the NHS trusts (in the eSALT case study) or their research cohort (in the ePACT case study). Willingness to participate was high amongst parents, being that current levels of speech and language therapy intervention are low and frequently related to eating and drinking rather than communication intervention (Gascoigne 2012).

In turn, the recruitment of therapists was straightforward, although the recruitment of families took longer than was anticipated by the research partners due to external difficulties such as the varying levels of parents' compliance with the research timeline, the pressures of their

workload and the small number of parents with potential for inclusion. We found that the specialist therapists were in a good position to recruit as they were in close contact with families from the diagnosis of children with special needs. Thus, other therapeutic members of a child's team may potentially be recruited for future studies; for example, physios may become available because they have more contact time at this stage.

Although the recruitment process was facilitated by the organisational partners, it has also presented control of access challenges and constraints. In the recruitment stage, we had to negotiate a sample size that was suitable for both in-depth qualitative study (for this thesis) and clinical assessments (for the clinical partner research). We have also come to realise the various challenges of working with parents of children with disabilities, including the difficulty of recruiting from this population, the impact of lengthy participation requirements on participants and the high dropout rates that are a characteristic of this group (Hinojosa 1990; McGoron & Ondersma 2015).

In addition, the clinical partners restricted our access to specific data during the data collection stage - such as having access to participants' contact information - while they also deleted videos shared through the field deployment experiment with no previous notice. We found that these restrictions delayed the design process and analysis which, as we would suggest, has resulted from the lack of upfront agreement on shared ownership and control of the research data (Karnieli-Miller et al. 2008).

Furthermore, the KeepCam field deployment (Chapter 5) was strongly influenced by clinical partner requirements. With regard to clinical research, the partners were more concerned about the deployment of an intensive therapy programme, supported by a digital solution, which gave them the ability to measure the clinical impact. Therefore, the ePACT partners were rushing the design process in order to start the deployment and clinical assessment phase.

The field deployment of KeepCam was also conducted in parallel with clinical measurement requirements (Appendix X). For instance, the therapists were looking to measure child development through video captured three times per week using GoPro cameras while accelerometery devices were attached to the child. The mothers reported that video recording

with GoPro cameras was invasive because the whole home environment was captured and was too difficult to set up, while smartphones would make it far easier to capture behaviour.

The therapists reported that the mothers' compliance with the clinical assessment method was low, but even mothers who were very interested in the study found it difficult to complete all recordings (e.g. only one mother managed to deliver the full clinical data set throughout the deployment). Consequently, the KeepCam field deployment was affected by the overwhelming level of clinical assessment requirements. We realised that the participants' retention rate was high in the design phases, yet the clinical assessment requirements potentially affected their engagement in the deployment phase. For instance, two mothers dropped out at the beginning of the deployment and one mother provided an intervention over a period of three weeks before dropping out.

The various experiences and challenges of the power relationships with clinical partners have demonstrated the need for methodological considerations to guide the partnership process. From the outset of our research, the role, responsibilities and nature of the partnership should be clearly defined and shared. It is also important to emphasise the vital role of the design process in HCI by sharing previous experiences in different contexts. As a result, trust in the design process and the design researcher can be realised before and not during the period in which the research was conducted.

8.3.4 *Organisational Regulations and Politics*

This research has proposed a variety of relational and technological changes within the indirect therapy service context. Working in the context of healthcare services requires awareness of the regulations and policies imposed by the healthcare organisation in order to understand the operational context. For sustainable and dependable change, adjustment to the organisational systems might be required to implement the technological solution in the organisational context. Although there is clear value to designing a healthcare solution within the organisational structure that was realised in the ePACT case study, we have faced obstacles to the design process and the participants' engagement.

Initially, conducting research with the NHS systems was deemed as a challenging experience that consumed time and effort in view of the researcher's time and resources being limited. For instance, in the ePACT case study we spent around nine months accessing the ethical

approval and receiving the research passport. The lengthy ethical procedures imposed an additional challenge and delay in the early stages of this research, which was followed by an unanticipated delay in the recruitment process.

Furthermore, through the design activities and discussions involving the participants (i.e. therapists), we discovered that various NHS trusts employed different information governance policies. These policies provide a governance framework for the use of data within the healthcare organisation that sets laws to protect both the rights of patients (e.g. privacy) and the responsibilities of healthcare staff and researchers (e.g. procedures employed for confidentiality and patient's data protection). However, these regulations were defined differently in each NHS trust. Some trusts prohibit the exchange of confidential patient data beyond the NHS mailing servers (see North Durham NHS Foundation Trust policy below), while other trusts allow exchange of data through commercial emails upon the patient's request (see Newcastle Foundation Trust policy below).

> *"Staff must be careful when sending emails containing personal identifiable / commercially sensitive information via email. The minimum information should be sent via email. Both sender and recipient in NHS organisations must have an NHS mail account ending in @nhs.net"* [North Durham NHS Foundation Trust]

> *"Patients may request to receive correspondence by email or text messaging. The patient's request to receive clinical and other personal information via email, or other electronic forms, must be recorded in the patient record. The patient must be informed that responsibility for the confidentiality of the received correspondence rests with them and their personal communication service provider (email or text messaging)."* [The Newcastle upon Tyne Hospitals NHS Foundation Trust]

In addition to the regulatory variations between trusts, these policies were also perceived differently by the therapists. For instance, some of the therapists indicated that they never respond to patient emails in order to avoid threatening confidentiality, even if the trust allowed exchange of patient data based on their consent. On the other hand, information governance rules have also affected and delayed the therapists' engagement in the design process.

Initially, in the first phase of the eSALT case study shown in Chapter 3, the therapists' thinking was restricted by what the information governance allowed them to do; that is, they were not able to discuss solutions "out of the box" of NHS regulation. However, this challenge was alleviated in the design workshop as they became more familiar with the design research process, leading us to suggest that the concrete design activities facilitated the innovation process. In this respect, regardless of the value of working directly within the healthcare organisational structure, we found that information governance rules are one of the biggest issues facing the design and adoptability of sociotechnical solutions.

These issues resulted from the demand for change in the associated organisational procedures. As a result, we have come to recognise the need to engage the organisational decision-makers in the design process in order to unify and permit changes that improve the current relational healthcare model (Darlington 2012).

8.4 Conclusion

Parent-delivered therapy is one of the important practices used to promote the development of children with special needs at a very young age. The primary aim of this thesis has hence been to explore the existing norms, contextual challenges and models of support for the indirect therapy programmes delivered to the parents of children with cerebral palsy or autism. In addition, this thesis has set out to investigate design strategies and digital solutions to promote therapy adoption in the children's natural environments and augment the relational healthcare system.

Our study has hence been motivated by the impact of early therapy intervention in improving pre-school children's communication skills before they reach school age, which was challenged by the lack of regular contact with professional therapists and the demand for continuity of support that influenced the compliance of parents and therapy outcomes. Therefore, a multi-pronged qualitative approach has been conducted in this research to explore this area further and to document, design, deploy and review two therapy intervention protocols: eSALT and ePACT. Both case studies have been conducted through partnerships with clinical research collaborators (the Institute of Health and Society and the PACT clinical research team) and design engagement with various sources, including therapists and mothers.

Our findings have added substantially to our understanding of the issues surrounding parent-delivered therapy and the mothers' communication of their needs in terms of engagement, reassurance and feedback about home practices. We found that home therapy is based on coaching principles and requires continuous motivation and persistence in adapting the home practices. In addition, we have identified a real potential for developing less formal communication platforms led by parents to support them through self-reflection and social channels, and not just for professional care service delivery.

In indirect therapy, the parents have played the role of the coachee with the professional, while the position of the coach has been to intervene with the other caregivers for their children. We have thus recognised the need to empower the parent's self-expertise and their central role within the indirect therapy programmes, while addressing surrounding issues of coordination and communication with professional therapists and members of their wider caregiving network.

We acknowledge that designing for cooperation and social support is crucial in various contexts for direct coaching of patients (Ulgado et al. 2013; Mamykina et al. 2008; Owen et al. 2004) or caregiver coaching (Liu et al. 2011; Schorch et al. 2016; Kientz & Abowd 2009; Marcu et al. 2012). For the purposes of this research, we have identified a number of design implications for future parent-driven video coaching solutions to support parents of pre-school children with special needs, from augmenting the current healthcare model and enhancing the communication with health professionals, to achieving better self-reflection, social support and sharing with their families and peer networks.

Eagerness to stimulate the children's communication skills was revealed by the parents and therapists, then facilitated through the deployment of a remote support solution. Remote therapy has reduced the need for frequent physical visits while maintaining a higher level of commitment compared to traditional service-delivery models. The solutions designed were realised as an external driver for continuous engagement with therapy programmes and to facilitate access to support. Additionally, the continuous contact and observed communication behaviours appeared to introduce new opportunities for the therapists to monitor home practices and achieve the generalisation of therapy principles.

Our exploration and design process for mobile video coaching in real therapy settings have revealed a number of opportunities to demonstrate the potential for the sensitive design of digital platforms with the objective of improving the therapeutic services provided to mothers of children with cerebral palsy or autism. Ultimately, we found that this mobile video coaching technology addresses a holistic parent-driven approach that is loosely coupled with the specific structure of therapy protocols and is more focused on facilitating self-reflection, communication, and collaboration. Through the reflection on both case studies, it has been possible to: 1) create a design concept for a sociotechnical coaching solution to support early speech therapy programmes, one resulting in a new parent-led relational healthcare model; and 2) inform the methodological engagement process through which the role of design and power relations in healthcare are investigated and where we, as HCI researchers, must ensure reconfiguring adoptable and sustainable digital solutions.

Summary of Contributions

The thesis has introduced three main contributions. Firstly, the research has contributed to an under-investigated and under-represented area of HCI - known as parent-delivered speech therapy programmes - with a rich and in-depth holistic contextual understanding of the existing therapy practices and the challenges facing parents within the children's caregiving network, along with their technological and social needs and design opportunities. This objective has been achieved through consideration of long-term-engagement case studies in two different therapy settings in England.

Secondly, the thesis further contributes an empirical design to leverage indirect therapy practices through informal communication channels and extend professional and social support. Here, we have introduced the design implications of a parent-led cooperative therapeutic model to enable communication, collaboration, empowerment and self-reflection in indirect therapy programmes. Our objectives have been realised through the co-design process of the KeepCam and ePACT technologies and their potential in improving the current relational healthcare model for early speech and language therapy.

Thirdly, this study has contributed to a body of interdisciplinary research that combine various qualitative design approaches and involve various stakeholders, including parents and therapists, to design digital interventions within indirect therapy contexts for and with

mothers of children with special needs. This project has been achieved through partnership with clinical researchers and constitutive conceptualisation of participation, along with utilising, redesigning and innovating design methods responsive to the participants, context and investigatory research needs.

Limitations and Future Directions

Although the research uses ubiquitous capture and sharing technology to facilitate remote coaching and promote therapy adoption, its field deployment faces some limitations. The therapy was delivered by only one research therapist who was not involved in any clinical caseloads during the deployment period. This approach has made it difficult to argue the generalisability of the findings, being that we cannot predict the effects of the integration of the digital solution into real clinical practices and how they could impact the therapists' workload. Moreover, the continuous contact and observed communication behaviours appear to create an additional burden on the therapists. In fact, the duration of the deployment intervention was considered too short for children with special needs to see significant improvements in their communication skills.

We would therefore conclude that extended deployment is warranted to explore the design's effectiveness in early intervention with clinical therapists and with less frequent home visits. Future research should also focus on controlled trials with pre- and post-clinical assessment to explore the effect of continuous support on children's communication development. In addition, methodological approaches to action research echo the reality that sustainable and genuine adoption of technology is crucial to evaluate its real impact and provide opportunities to extend the research to investigate the relevant organisational changes (Hayes 2011). Further studies can then focus on evaluating and reiterating the deployment of parent-led coaching technology within the healthcare organisational structure.

Furthermore, even when taking account of the genuine opportunities for such digitally augmented therapy regimes, we also need to address the many barriers to incorporating coaching technologies into the current clinical practices and regulations of the National Health Service (UK). Therefore, in order to truly empower parents, it is necessary to involve decision-makers from the NHS in the design process to address the organisational change,

review the information governance regulations and policies, and to truly realise the value and need for remote support to improve the healthcare service delivery model.

Finally, we found that the mothers of pre-school children with special needs are responsible for the delivery of multiple home therapy programmes and coordination among the multidisciplinary team. We also noted that early therapy programmes employ similar protocols that include home visits for coaching, assessment and follow-up. Both case studies showed the similarity of coaching techniques for mothers of children with CP and mothers of children with autism. Future recruitment could hence involve more physiotherapists, occupational therapists, teaching assistants and parents of children with various developmental delays. Future research would thus benefit from expanding the contextual investigation to involve the multidisciplinary team in the design process in order to discover the experiences and challenges of home therapy programmes from their point of view. Similarly, by involving the parents of children with various developmental delays and conditions, we can identify the common issues imposed by home therapy programmes. In this way, we could explore how the design implications extend to other home therapeutic practices and health conditions.

Appendices

Appendix A. eSALT Contextual Inquiry Phase

Accompanies Chapter 3

Interview Guide for Parents

Overview

- Can you tell me about your everyday family life?
  Probes:
  - mother's daily routines (working vs. leisure time)
  - partner and family routines
  - relationships within the family and communication routines
  - relationships with relatives and communication routines
- Could you tell me more about (child) abilities and strengths?
  Probes:
  - goals, values and feelings towards the child
  - caregiving needs
  - diagnosis
  - pre-diagnosis and post-diagnosis support
  - therapy programmes
  - peer network
- What are the caregiving activities you do with (child)? Why?
  Probes:
  - mother's involvement and associated feelings
  - other responsibilities
- What is the most helpful type of support for your caregiving responsibility?
  Probes:
  - importance of relative/friends/peers, why
  - sources of information
  - coping strategies

Parent-Delivered Therapy

- Can I ask you about the therapy programme?
  Probes:
  - visit duration, home vs. clinic, frequency
  - communication between visits
  - impact on the mother-child interaction and family members
- What does the therapist do during the sessions?
  Probes:
  - guidance, trust and feelings
  - any material provided

- What did you expect from the therapy programme in the first session?
  Probes:
    - effectiveness of home practices
    - limitations
- What do you want to change about the therapy programmes?
  Probes:
    - improvements
    - knowledge, experience and confidence

Home Practices

- How you usually practice the therapy at home?
  Probes:
    - what, when, where, how
    - commitment
    - challenges
    - follow-up and support mechanisms
- How to improve and learn more practices for home therapy?
  Probes:
    - learning style
    - sources of information
    - self-discovery and self-esteem
- What was the effect of these home therapy practices on your interaction with (child)?
  Probes:
    - play and communication
    - caregiving
- What was the effect of these home therapy programmes on your family?
  Probes:
    - changes within family
    - coping strategies

Use of Technology

- Have you ever recorded videos of (child)? Can you tell me about that?
  Probes:
    - what to record, why
    - where, when, pre-planned or not
    - equipment used, why
    - show me and tell me
- Have you shared these recording with others?
  Probes:
    - with whom, why
    - frequent of sharing – like in the last week
- Which application you usually use to share these videos? And why have you chosen it?
  Probes:
    - social media
    - privacy concerns
- How do you use digital technology to support your child communication development?

Interview Guide for Therapists

Overview

- Can I ask you to tell me about your daily working routines?
  Probes:
  - work load and duration
  - home visits
  - challenges
- Could you tell me more about the children's condition that you are working with?
  Probes:
  - experience with various disabilities

Parent-Delivered Therapy

- Could you tell me more about working on "parent-delivered therapy" in your trust?
  Probes:
  - start at which age
  - programme duration
  - home vs. clinic
  - sessions duration and frequency
  - sessions attendees and location at home
- What do you usually do during the therapy sessions?
  Probes:
  - teaching strategies, how
  - material and tools provided
  - goals/targets settings
  - outcomes assessment
  - evidence presented by parents
  - how to communicate info to the parent (assessment, goals and expectations)
  - parents' feelings toward input
  - session challenges
- What do the parents discuss during these sessions?
  Probes:
  - needs and challenges
  - support mechanisms and limitations
  - professionalism vs. support
- What are the communication methods with families between visits?
  Probes:
  - contact details: personal or work, phone or email
  - initiated by?
  - reasons to communicate

Perspectives on Parent-Delivered Therapy

- From your perspective, how does the parent-based programme affect the families?
  Probes:
  - mother-child relationship
  - other family members

- What are the challenges of delivering a parent-based programme?
  Probes:
    - first visit
    - family commitment
    - conflicts with other sources of information (online or experienced family members)
- How would you describe the social support role for these families?
  Probes:
    - support groups for families
    - introducing peer families

Potentials of Coaching Technology

- What is the potential use of video to support remote therapy?
  Probes:
    - data collected
    - integration in therapy practices
- How could the video facilitate discussions with parents remotely?
  Probes:
    - pros and cons
- Are there any video recording requirements to be considered by the parents?
  Probes:
    - distance, objects, people
    - recording scenarios
- Based on the sample recording presented showing a parent-child play:
    - What would be the optimal video duration to capture the therapists' input?
      Probes:
        - balance work load vs. missing interactions
    - What would you advise the parent based on the observed interaction?
      Probes:
        - type of advice and guidance
        - referring to specific moments

Appendix B. eSALT Co-Design Phase

Accompanies Chapter 4

Persona

Mum: **Debbie** – 32 years old

Child: **Harry** – 2 years old

Debbie is a part-time working mother and Harry is her first child. Harry was recently diagnosed with speech and language delay, where they start receiving visits from **Speech and Language Therapist (SALT)** to encourage communication.

Debbie has had 2 home sessions with SALT and is practising the strategies she has learnt during their play routine. The recent communication strategies she has learnt are: **face-to-face, wait, watch and listen.**

Scenario 1

Debbie is playing with Harry on the floor of their living room. Harry has chosen to play with a car. Harry is pushing the car back and forward, and occasionally looking up at Debbie.

Debbie gets face to face with Harry. She says 'Brrrm, brrrm' as Harry plays with the car. Harry looks up at Debbie and smiles then pushes the car around again. Debbie takes this as a sign to continue making the sound 'Brrm, brrm'. Harry looks up at Debbie, smiles again and then goes back to pushing the car. Debbie clicks the selfie-button here to record the last minute.

She sends it to the SALT, commenting…

Debbie: I got face-to-face when Harry was playing; it was easier for me to get involved with what he was doing. He's started to look at me more when we're playing in this kind of position.

SALT: By being face-to-face you can easily see what Harry is doing and start to interpret his body language and movements to communicate. He really enjoyed what you were doing when you made the car noise and you responded exactly right.

Next time wait a bit longer to see if he will request you to make the sound again. Try counting to 5 in your head to help you wait, it might feel like a long time but give it a few tries to see what happens.

Scenario 2

Harry and Debbie are playing with cars again on the floor. Debbie has been making the same 'Brrm, brrm' noise while Harry is playing, and he has been sharing smiles and eye contact again. Debbie tries out the advice of the SALT.

Debbie waits while Harry plays with the car and when Harry looks up at Debbie again, she waits a little longer to see what he will do. Harry looks at Debbie and makes a sound 'Buh', while Debbie says 'Yes, that's the car' but does not repeat the 'Brrm, brrm' noise. Harry smiles back and then goes back to playing with his car. Debbie clicks the selfie-button here to record the last minute.

She sends it to the SALT, commenting…

Debbie: Harry made a sound, but I wasn't sure what to do. What should I do when he makes a sound while we're playing like that?

SALT: Great work watching and listening. Harry made a sound, which is excellent progress. It can be difficult when the sound doesn't sound like a word, but what do you think he might have been asking?

Debbie: I thought he might be asking me to do it again, but I wasn't sure.

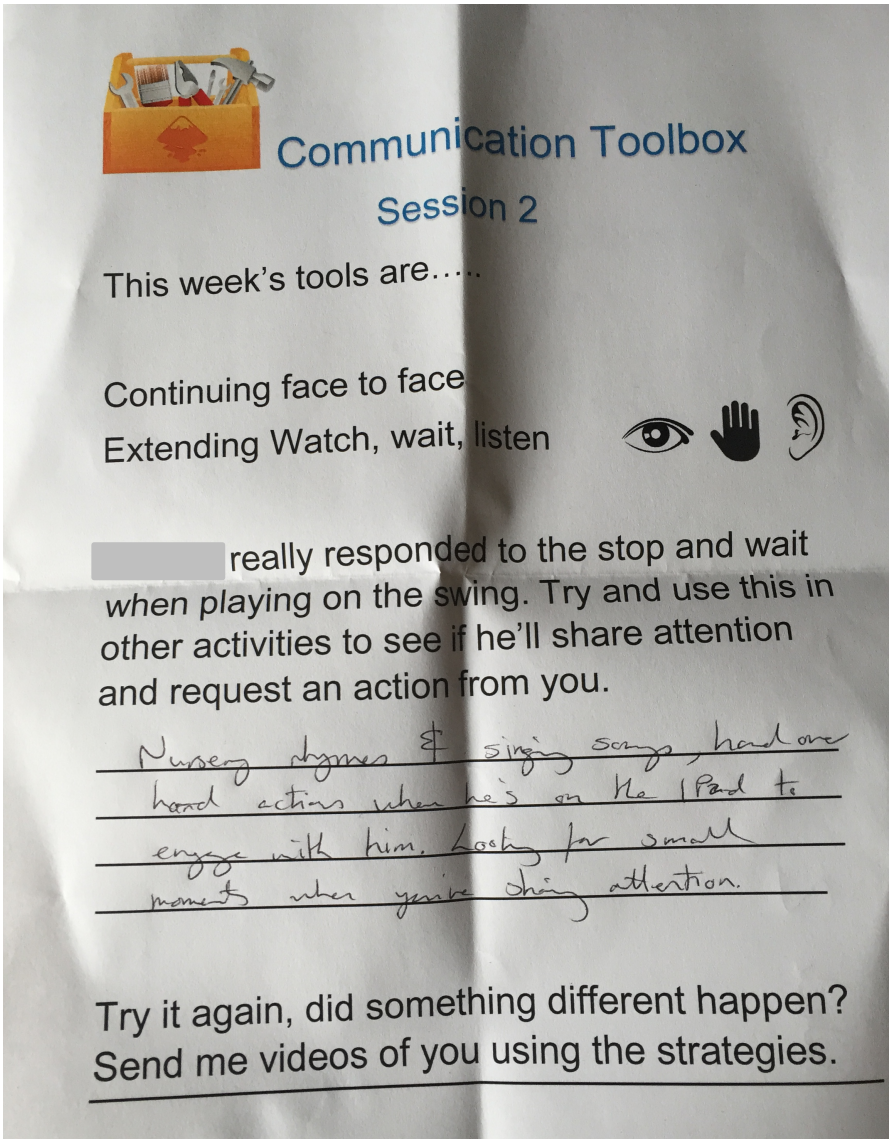
SALT: I think you're right! Try waiting again for another turn and see if he makes the sound again.

You could also use the word 'Again?' and wait to see if he responds to this. If not, don't worry repeat 'again' and make the noise. By using 'Again?' you're using a word that he can use in lots of play routines to repeat an enjoyable action, while he may start using it more often in different activities.

Appendix C. eSALT Field Deployment Phase

Accompanies Chapter 5

Samples of "My Communication Toolbox" Practice Sheets



Communication Toolbox

Session 2

This week's tools are…..

Continuing face to face

Extending Watch, wait, listen

[redacted] really responded to the stop and wait *when playing* on the swing. Try and use this in *other* activities to see if he'll share attention and request an action from you.

Nursery rhymes & singing songs, hand over hand actions when he's on the iPad to engage with him. Look for small moments when you're sharing attention.

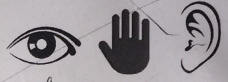
Try it again, did something different happen? Send me videos of you using the strategies.

Communication Toolbox

Session 6

This week's tools are.....

Watch, wait, listen



Turn taking, adding language, target words

[redacted] is starting to use a few single words to get his needs met. Try and think of words that would be useful for him to try and add these into your play routines.

Try 'Go', 'More', 'Yes', 'No'.
Play routine with the box, song to introduces, have some favourite toys for [redacted] to find & name.

When is [redacted] using words most? Send me videos of you using the strategies.

Field Study Interview Guide for Parents

Overview

- Can I ask you about the SLT you had as part of the study?
  Probes:
  - frequency and length of the visits
  - things learned during the visits – content
  - material provided – like/dislike, shared with others
  - content understanding and ability to share with family
  - observed changes with child and mothers
  - progression between visits compared to other home therapy programmes
  - keepCam during the visits
- Can you tell me about your experience of using the KeepCam between the visits and how generally you used it?
  Probes:
  - engagement level
  - impact on their daily routine
  - how does using it fit with personal use of your phone, its use for therapy or its use for social purposes?

KeepCam app for data capture

- How have you filmed your interactions with [Child]?
  Probes:
  - selfie-button, tripods, front/back camera
  - when they filmed the interactions/planned or random time
  - where they filmed interactions (inside home, garden, outside home)
  - play scenario
  - people in the scene
  - duration of the clip vs. extending the recording
  - reaction of the mother and the child for being filmed
  - reminders needed
  - issues faced
- Can you tell me roughly how many videos filmed per week? and in total?

KeepCam app for data sharing

- Can you tell me roughly how many videos shared per week?
  Probes:
  - selection of videos to share over other video made
  - editing before sharing, why?
  - sharing through KeepCam vs. other apps
  - time spent sharing and adding comments video
  - time spent using KeepCam app each week to share or review (10m, 15m, 30m)
  - issues faced
- How do you find the support received through the app between the visits?
  Probes:
  - feeling about the continuous support
  - feeling about the feedback received (content, volume)
  - feeling about contacting the therapist between visits
  - immediacy of responses vs. engagement, types of responses received

Additional

- Have you used the applications after the therapy intervention?
  Probes:
    - for reflection and remembering strategies
    - to observe changes
- Have you used the therapy material after the therapy intervention?
- Do you have any recommendations to improve the KeepCam?
  Probes:
    - new ideas for design
    - acceptable no. of video to share per week
    - acceptable time for responses
- Do you have any recommendations to improve the SLT services provided?
- How do you think the applications would work with other therapists?

Field Study Interview Guide for Therapist

Overview

- Can you tell me about the SLT you provided as part of the study?
  Probes:
    - frequency and length of the visits
    - fixed schedule or arranged week-by-week
    - things done during the visits – content
    - material provided – like/dislike, how does it work
    - mothers' understanding and ability to practice
    - observed changes with child and mothers
    - progression between visits
    - used the app during the visits
- Can you tell me about your experience of using the applications between the visits and what you did in general?
  Probes:
    - engagement level
    - understanding of the context
    - impact on their working routine

KeepCam app for data capture

- How did you find the filmed interactions with the children?
  Probes:
    - showing the right things
    - people in the scene
    - doing what - related to therapy or mixed
    - any instructions provided
    - ideal duration
    - reaction of the mother and the child to being filmed
    - reminders needed
    - issues faced

KeepCam app for data sharing

- Can you tell me roughly how many videos were shared per week from each mother?
  Probes:
    - asking for what
    - any missing content
    - time spent to check and annotate video
    - time spent using KeepCam app each week to review and reply (10m, 15m, 30m)
    - issues faced
- How do you find the support provided through the app between the visits?
  Probes:
    - impact of the continuous support
    - feeling about the feedback provided (content, volume, type – txt/video)
    - feeling about contacting the therapist between visits and being contacted
    - immediacy of responses vs. engagement
    - type of responses sent

Additional

- Have you reviewed the KeepCam content for things other than responding to the mothers?
  Probes:
    - to reflect and remind yourself about the child's situation and stage
    - to observe changes
- Do you have any recommendations to improve the applications?
  Probes:
    - ideas to improve the design
    - acceptable no. of video to share per week
    - acceptable time for responses
- How would you improve the SLT services provided?

Appendix D. ePACT Contextual Inquiry Phase

Accompanies Chapter 6

Preschool Autism Communication Therapy (PACT): Stages and Strategies

From PACT Manual - Aldred, C.R. et al., 2011. *PRE-SCHOOL AUTISM COMMUNICATION THERAPY (PACT)*, Available at: http://onlinelibrary.wiley.com/doi/10.1901/jaba.2002.35-213/abstract.

STAGE 1. ESTABLISHING SHARED ATTENTION

- The child chooses.
- Following.
- Maintaining shared attention.
- Waiting and watching.
- Sharing the child's interest.
- Mirroring.
- Positioning.
- Managing arousal levels.

STAGE 2. SYNCHRONICITY AND SENSITIVITY

- Reduced demands on the child's attention and processing.
- Reducing expectation on the child to act in a particular way.
- Matching the child's initiation, pace, and activity.
- Commenting and Rephrasing.
- Acknowledging the child's actions and communications.
- Social routines and songs.
- Use of appropriate praise.
- Maintaining skills from the earlier stage.

STAGE 3. FOCUSING ON LANGUAGE INPUT

- Language mapping.
- Modelling language.
- Additional strategies to support language development.
- Imitation.

- Repetition.
- Consistency.
- Matching child's language level.
- Semantic contingency.

STAGE 4. ESTABLISHING ROUTINES AND ANTICIPATION

- Repetition.
- Anticipation.
- Pause.
- Imitation of words.
- Familiar routines/rhymes.
- Repetitive scripts.

STAGE 5. INCREASING COMMUNICATION FUNCTIONS

- Breaks/pauses in familiar routines.
- Communication opportunity games/situations (see table below for definitions and ideas).
- Discussing useful equipment items e.g. toys with pieces missing, a pop-up toy with one pop up man missing, puzzle with a piece missing, bubble pot with wand missing, balloon pump but no balloons, drum with no drumstick, pencils (but no paper or vice versa), nesting/stacking toys with one or more pieces missing, broken toys e.g. tangled slinky, pop up toy that doesn't pop up any more (one that is already known to the child).

STAGE 6. EXPANDING LANGUAGE AND CONVERSATIONS

- Repeating back.
- Rephrasing.
- Use of re-casts.
- These are discussed in more detail on the following pages.

Northumberland, Tyne and Wear NHS
NHS Foundation Trust

PACT Home Programme (session 1)

Name: **X** **DOB:**
Date: 30/08/16

Stage and focus:
X is working at the joint attention stage. He is focussing on leading the play and letting others join in.

Equipment:
Today X was very focussed on the click clack track. It was lovely to see how exited he was when the cars went down, showing it with his whole body. He seemed to enjoy the frog in the box briefly but find this a little overwhelming.

Summary of achievements:
You read X's nonverbal communication really sensitively to know when to push him and when to sit back. You found non demanding ways to gently ease your way into his play. You kept the play exciting by building in anticipation by playing ready steady go with the car track. You made eye contact as easy as possible by getting down on X's level.

New skills:
X really focussed on the click clack track showing great attention skills. He coped really well with letting you join in with his play on his terms.

X needs help in the following areas:

- Looking from the toy he is focussed on to his communication partner
- Sharing his enjoyment with others

Aims for home practice:

- To get down on X's level when playing
- To play with the same item X is, finding a way to gently ease into his play.

Ideas:

- Sit back and let X pick the activity.
- If X focusses on the same thing for a long time that's fine, we talked about how repetition is soothing for him, and practice makes perfect!
- Remember to keep the demands low, it's ok if X needs to take a break. He's working hard at this.

Date of next session: 12/09/16 @ 5pm

Ruth Madeley, Research Speech and Language Therapist

PACT Home Programme Session 4

Name: **X** **DOB:**
Date: **11/11/16**

Stage and focus:
X is working at the 'synchrony' stage. Matching his language and play activities with an adult's.

Equipment:
This week X chose to bring his own toys to play with. He played with his ball run, click clack, wind up robots and wind up bikes.

Summary of achievements:
This was another lovely session. X was focussed on you despite the busy environment. You accepted and responded to all his communication without placing any demands on him (for example waiting for eye contact) and he responded by giving you really natural eye contact (with lovely cheeky smiles). The session was really relaxed, with limited language and X leading the play

New skills:
X used lots of really natural triadic gaze, pairing it with some lovely smiles. His communication was really clear and he's obviously really confident that that you will respond to him and play in the way that he wants.

X needs help in the following areas:

- X needs more practice leading the pace of the interaction and experiencing interaction with minimal demands.

Aims for home practice:

- To keep demands minimal, accepting and responding to all X's communication.
- Let X set the pace.

Ideas:

- Keep letting X lead the play.
- Keep the demands low, with little language and no questions.
- Keep mimicking X's vocalisations.
- Keep looking out for X using triadic gaze.

Date of next session21/10/16 @ 10.00 pm

Ruth Madeley, Research Speech and Language Therapist

References

AAP, 2011. Is Your Toddler Communicating With You? *American Academy of Pediatrics*. Available at: https://www.healthychildren.org/English/ages-stages/toddler/Pages/Language-Delay.aspx.

Aggarwal, D. et al., 2015. Understanding Video based Parent Training Intervention for Children with Autism. In *Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction on - OzCHI '15*. pp. 10–19. Available at: http://dl.acm.org/citation.cfm?doid=2838739.2838770.

Aldred, C.R. et al., 2011. *PRE-SCHOOL AUTISM COMMUNICATION THERAPY (PACT)*, Available at: http://onlinelibrary.wiley.com/doi/10.1901/jaba.2002.35-213/abstract.

Allen, K. & Huff, N., 2014. Family Coaching: An Emerging Family Science Field. *Family Relations*, 63(5), pp.569–582. Available at: http://doi.wiley.com/10.1111/fare.12087.

Amir, O. et al., 2015. From Care Plans to Care Coordination: Opportunities for Computer Support for Teamwork in Complex Healthcar. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*. pp. 1419–1428. Available at: http://dl.acm.org/citation.cfm?doid=2702123.2702320.

Ammari, T., Morris, M.R. & Schoenebeck, S.Y., 2014. Accessing Social Support and Overcoming Judgment on Social Media among Parents of Children with Special Needs. In *Proceedings of the Eighth International AAAI Conference on Weblogs and Social Media Accessing*. pp. 22–31. Available at: http://doi.acm.org/10.1145/2858036.2858210.

Amorose, A.J. & Horn, T.S., 2000. Intrinsic motivation: Relationships with collegiate athletes' gender, scholarship status, and perceptions of their coaches' behavior. *Journal of sport and exercise psychology*, 22(1), pp.63–84.

Andersen, G., Mjøen, T.R. & Vik, T., 2010. Prevalence of Speech Problems and the Use of Augmentative and Alternative Communication in Children With Cerebral Palsy: A Registry-Based Study in Norway. *Perspectives on Augmentative and Alternative Communication*, 19(1), pp.12–20. Available at: http://sig12perspectives.pubs.asha.org/article.aspx?doi=10.1044/aac19.1.12.

Årsand, E. & Demiris, G., 2008. User-centered methods for designing patient-centric self-help tools. *Informatics for Health and Social Care*, 33(3), pp.158–169.

ASHA, 1925. The American Speech-Language-Hearing Association. Available at: http://www.asha.org.

Bailey, A. et al., 1995. Autism as a strongly genetic disorder evidence from a british twin Study. *Psychological Medicine*, 25(1), pp.63–77.

Baker-Ericzen, M.J., Brookman-Frazee, L. & Stahmer, A., 2005. Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30(4), pp.194–204.

Baker-Ericzn, M.J., Brookman-Frazee, L. & Stahmer, A., 2005. Stress Levels and Adaptability in Parents of Toddlers With and Without Autism Spectrum Disorders. *Research and Practice for Persons with Severe Disabilities*, 30(4), pp.194–204. Available at: http://rps.sagepub.com/lookup/doi/10.2511/rpsd.30.4.194.

Balaam, M., Robertson, J. & Fitzpatrick, G., 2013. Motherhood and HCI. In *CHI'13 extended abstracts on human factors in computing systems*. pp. 3215–3218.

Balldin, S., Fisher, P. & Wirtberg, I., 2018. Video Feedback Intervention With Children: A Systematic Review. *Research on Social Work Practice*, 28(6), pp.682–695. Available at: http://rsw.sagepub.com/cgi/doi/10.1177/1049731516671809.

Bardzell, J., Bardzell, S. & Koefoed Hansen, L., 2015. Immodest proposals: Research through design and knowledge. In *In Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. pp. 2093–2102.

Baron, L. & Morin, L., 2009. The Coach–Coachee Relationship in Executive Coaching: A Field Study. *Human Resource Development Quarterly*, 20(1), pp.85–106.

Barry, F., 2012. Talking Tips for Kids. Available at: http://www.talkingtipsforkids.com/.

Baxendale, J. & Hesketh, A., 2009. Comparison of the effectiveness of the Hanen Parent Programme and traditional clinic therapy. *International Journal of Language & Communication Disorders*, 38(4), pp.397–415.

Baxter, G. & Sommerville, I., 2011. Socio-technical systems: From design methods to systems engineering. *Interacting with Computers*, 23(1), pp.4–17. Available at: http://dx.doi.org/10.1016/j.intcom.2010.07.003.

Bayat, M., 2007. Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), pp.702–714.

Bennett, J.A. et al., 2005. Healthy Aging Demonstration Project: Nurse Coaching for Behavior Change in Older Adults. *Research in Nursing & Health*, 28, pp.187–197.

Benton, L. et al., 2012. Developing IDEAS : supporting children with autism within a participatory design team. In *Proceedings of the SIGCHI conference on Human factors in computing systems*. pp. 2599–2608. Available at: http://dx.doi.org/10.1145/2207676.2208650.

Bercow, J., 2008. *The Bercow Report: A review of services for children and young people (0-19) with speech, language and communication needs*, Nottingham: DCSF. Available at: https://www.education.gov.uk/publications/eOrderingDownload/Bercow-Report.pdf.

Birbeck, J. et al., 2015. *Video enhanced reflective practice: Professional development through attuned interactions*, Jessica Kingsley Publishers.

Bogers, S., Kollenburg, J. van, Rutjes, H., et al., 2018. A Showcase of Data-enabled Design Explorations. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems*. pp. 1–4.

Bogers, S., Kollenburg, J. van, Deckers, E., et al., 2018. A Situated Exploration of Designing for Personal Health Ecosystems through Data-enabled Design. In *Proceedings of the 2018 on Designing Interactive Systems Conference*. pp. 109–120.

Boisvert, M. & Hall, N., 2014. The use of telehealth in early autism training for parents: a scoping review. *Smart Homecare Technology and TeleHealth*, 2, pp.19–27. Available at: http://www.dovepress.com/the-use-of-telehealth-in-early-autism-training-for-parents-a-scoping-r-peer-reviewed-article-SHTT.

Bowen, S. et al., 2013. How was it for you? Experiences of participatory design in the UK health service. *CoDesign*, 9(4), pp.230–246. Available at: http://dx.doi.org/10.1080/15710882.2013.846384.

Bowyer, A. et al., 2018. Understanding the Family Perspective on the Storage, Sharing and Handling of Family Civic Data. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. pp. 1–13.

Boyd, B.A., 2002. Examining the Relationship Between Stress and Lack of Social Support in Mothers of Children With Autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), pp.208–215.

Braun, V. & Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp.77–101.

Brehaut, J.C. et al., 2004. The Health of Primary Caregivers of Children With Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers? *Pediatrics*, 114(2), pp.e182–e191. Available at: http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.114.2.e182.

Brobst, J.B., Clopton, J.R. & Hendrick, S.S., 2009. Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), pp.38–49.

Burgess, S., Audet, L. & Harjusola-Webb, S., 2013. Quantitative and qualitative

characteristics of the school and home language environments of preschool-aged children with ASD. *Journal of Communication Disorders*, 46(5–6), pp.428–439. Available at: http://dx.doi.org/10.1016/j.jcomdis.2013.09.003.

Buunk, B.P., Schaufeli, W.B. & Ybema, J.F., 1994. Burnout, Uncertainty, and the Desire for Social Comparison Among Nurses. *Journal of Applied Social Psychology*, 24(19), pp.1701–1718.

Cairns, P. & Cox, A.L., 2008. *Research Methods for Human-Computer Interaction*, Cambridge University Press.

Cason, J., 2011. Telerehabilitation: an adjunct service delivery model for early intervention services. *International journal of telerehabilitation*, 3(1), pp.19–30. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4296801&tool=pmcentrez&rendertype=abstract.

CDC, 2018. Autism Spectrum Disorder (ASD). *Centers for Disease Control and Prevention*. Available at: https://www.cdc.gov/ncbddd/autism/data.html.

Chakrabarti, S. & Fombonne, E., 2001. Pervasive Developmental Disorders in Preschool Children. *JAMA*, 285(24), pp.3093–3099.

Charman, T. & Baird, G., 2002. Practitioner Review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and ...*, 3(43), pp.289–305. Available at: http://onlinelibrary.wiley.com/doi/10.1111/1469-7610.00022/full%5Cnpapers2://publication/uuid/276EBB68-DE2F-44CC-BDB2-37DB6713D244.

Chen, Y., Ngo, V. & Park, S.Y., 2013. Caring for Caregivers: Designing for Integrality Yunan. In pp. 91–102.

Chien, M.E. et al., 2015. iCAN: A tablet-based pedagogical system for improving communication skills of children with autism. *International Journal of Human Computer Studies*, 73, pp.79–90. Available at: http://dx.doi.org/10.1016/j.ijhcs.2014.06.001.

Chung, H.-F. et al., 2016. Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. pp. 770–786.

Ciccia, A.H. et al., 2011. Improving the access of young urban children to speech, language and hearing screening via telehealth. *Journal of Telemedicine and Telecare*, 17, pp.240–244.

Clarke, M. & Price, K., 2012. Augmentative and alternative communication for children with

cerebral palsy. *Paediatrics and Child Health*, 22(9), pp.367–371. Available at: http://linkinghub.elsevier.com/retrieve/pii/S1751722212000443.

Clegg, J. et al., 2005. Developmental language disorders - A follow-up in later adult life. Cognitive, language and psychosocial outcomes. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 46(2), pp.128–149.

Coffman, S.P., 1983. Parents' Perceptions of Needs for Themselves and Their Children in a Cerebral Palsy Clinic. *Issues in Comprehensive Pediatric Nursing*, 6(1), pp.67–77.

Conway, M.A., 2005. Memory and the self. *Journal of Memory and Language*, 53(4), pp.594–628.

Coplan, J., 1985. Evaluation of the Child with Delayed Speech or Language. *Pediatric annals*, 14(3), pp.203–208.

Custodio, V.E., 2016. *VidCoach : A Mobile Video Modeling System for Individuals with Autism*.

Dale, P.S., Price, T.S. & Bishop, D.V.M., 2003. Outcomes of early language delay: I. predicting persistent and transient language difficulties at 3 and 4 years. *Journal of Speech, Language, and Hearing Research*, 46, pp.544–560.

Le Dantec, C.A. et al., 2011. Publics in Practice: Ubiquitous Computing at a Shelter for Homeless Mothers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. pp. 1687–1696.

Dantec, C.A. Le & Edwards, W.K., 2008. Designs on dignity: perceptions of technology among the homeless. In *CHI '08 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. pp. 627–636.

Darlington, R., 2012. *Human–Computer Interaction and International Public Policymaking: A Framework for Understanding and Taking Future Actions*, Available at: http://eprints.mdx.ac.uk/7914/.

Davis, E. et al., 2010. The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development*, 36(1), pp.63–73.

Dickson-Swift, V. et al., 2009. Researching sensitive topics: qualitative research as emotion work. *Qualitative research*, 9(1), pp.61–79.

Diggle, T. & McConachie, H., 2009. Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *The Cochrane Database of Systematic Reviews 2002*, (2), pp.2480–2482.

Diggle, T., McConachie, H. & Randle, V., 2003. Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *The Cochrane Database of*

Systematic Reviews 2002, (2).

Donetto, S. et al., 2015. Experiencebased co-design and healthcare improvement: Realizing participatory design in the public sector. *The Design Journal*, 18(2), pp.227–248.

Dunst, C.J. & Trivette, C.M., 2009. Capacity-building family systems intervention practices. *Journal of Family Social Work*, 12, pp.119–143.

DuPaul, G.J. et al., 2017. Face-to-Face Versus Online Behavioral Parent Training for Young Children at Risk for ADHD: Treatment Engagement and Outcomes. *Journal of Clinical Child & Adolescent Psychology*, 00(00), pp.1–15. Available at: http://www.ncbi.nlm.nih.gov/pubmed/28715272%0Ahttps://www.tandfonline.com/doi/full/10.1080/15374416.2017.1342544.

Dykstra, J.R. et al., 2013. Using the Language Environment Analysis (LENA) system in preschool classrooms with children with autism spectrum disorders. *Autism*, 17(5), pp.582–594.

Ehn, P., 2008. Participation in Design Things. In *Design Things*. pp. 92–101.

Eliasson, A. et al., 2011. An ecological approach of Constraint Induced Movement Therapy for 2-3-year-old children: A randomized control trial. *Research in Developmental Disabilities*, 32(6), pp.2820–8.

Enderby, P. et al., 2013. *Beyond the Anecdote: Examining the need for, and provision of, AAC in the United Kingdom*,

Escobedo, L. et al., 2012. MOSOCO: A Mobile Assistive Tool to Support Children with Autism Practicing Social Skills in Real-Life Situations. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12*. pp. 2589–2598. Available at: http://dl.acm.org/citation.cfm?doid=2207676.2208649.

Fagá-Jr, R. et al., 2009. Context information exchange and sharing in a peer-to-peer community: a video annotation scenario. *Proceedings of the 27th ACM international conference on Design of communication - SIGDOC '09*, pp.265–272. Available at: http://portal.acm.org/citation.cfm?doid=1621995.1622048%5Cnciteulike-article-id:6484530%5Cnhttp://dx.doi.org/10.1145/1621995.1622048.

Fell, H. et al., 2004. visiBabble for reinforcement of early vocalization. In *ACM SIGACCESS Accessibility and Computing*. pp. 161–168. Available at: http://portal.acm.org/citation.cfm?doid=1029014.1028659.

Fereday, J. & Muir-Cochrane, E., 2006. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, 5(1), pp.80–92.

Fernandes, B., 2011. iTherapy: The Revolution of Mobile Devices Within the Field of Speech Therapy. *Perspectives on School-Based Issues - American Speech-Language- Hearing Association (ASHA)*, 12(2), pp.35–40.

Fey, M.E. et al., 2006. Early effects of responsivity education/prelinguistic milieu teaching for children with developmental delays and their parents. *Journal of Speech, Language and Hearing Research*, 49(3), pp.526–47.

Fivaz-Depeursinge, E., Corboz-Warnery, A. & Keren, M., 2004. The primary triangle: Treating infants in their families. *Treating Parent-Infant Relationship Problems: Strategies for Intervention*, p.123−151.

Fleck, R. & Fitzpatrick, G., 2009. Teachers' and tutors' social reflection around SenseCam images. *International Journal of Human Computer Studies*, 67(12), pp.1024–1036. Available at: http://dx.doi.org/10.1016/j.ijhcs.2009.09.004.

Floyd, C., 1984. A Systematic Look at Prototyping. In *Approaches to Prototyping*. Springer, Berlin, Heidelberg, pp. 1–18.

Foth, M. & Axup, J., 2006. Participatory design and action research: Identical twins or synergetic pair? In *In Proceedings of the Participatory Design Conference*. pp. 93–96.

Friedman, M., Woods, J. & Salisbury, C., 2012. Caregiver coaching strategies for early intervention providers: Moving toward operational definitions. *Infants and Young Children*, 25(1), pp.62–82.

Fukkink, R.G., 2008. Video feedback in widescreen: A meta-analysis of family programs. *Clinical Psychology Review*, 28(6), pp.904–916.

Gardner, M.R. et al., 2015. Perceptions of Video-Based Appointments from the Patient's Home: A Patient Survey. *Telemedicine and e-Health*, 21(4), pp.281–285. Available at: http://online.liebertpub.com/doi/10.1089/tmj.2014.0037.

Gascoigne, M., 2012. *Better communication: shaping speech, language and communication services for children and young people.*, London: RCSLT. Available at: http://www.rcslt.org/speech_and_language_therapy/commissioning/better_communication.

Gaver, W., 2012. What should we expect from research through design? In *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. pp. 937–946.

Gibson, L. & Hanson, V.L., 2013. Digital motherhood: How does technology help new mothers? In *Proceedings of the SIGCHI conference on human factors in computing systems*. pp. 313–322.

Gordon, A.M. et al., 2011. Bimanual Training and Constraint-Induced Movement Therapy in

Children With Hemiplegic Cerebral Palsy: A Randomized Tria. *Neurorehabilitation and Neural Repair*, 25(8), pp.692–702.

Green, J. et al., 2010. Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *The Lancet*, 375(9732), pp.2152–2160. Available at: http://dx.doi.org/10.1016/S0140-6736(10)60587-9.

Green, J. et al., 2015. *THE PAEDIATRIC AUTISM COMMUNICATION TRIAL - GENERALISED (PACT-G)*, Available at: http://www.medicine.manchester.ac.uk/pact/.

Green, S.E., 2003. "What do you mean 'what's wrong with her?'": Stigma and the lives of families of children with disabilities. *Social Science and Medicine*, 57(8), pp.1361–1374.

Grogan-Johnson, S. et al., 2010. A pilot study comparing the effectiveness of speech language therapy provided by telemedicine with conventional on-site therapy. *Journal of Telemedicine and Telecare*, 16(3), pp.134–139.

Gustavsson, S., Gremyr, I. & Sarenmalm, E.K., 2015. Designing quality of care - contributions from parents. *Journal of Clinical Nursing*, 25(5–6), pp.742–751.

Gustavsson, S.M.K., 2014. Improvements in neonatal care; using experience-based co-design. *International Journal of Health Care Quality Assurance*, 27(5), pp.427–438.

Hagan, J.F., Shaw, J.S. & Duncan, P.M., 2007. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* 3rd ed., The American Academy of Pediatrics.

Hailpern, J. et al., 2012. Designing visualizations to facilitate multisyllabic speech with children with autism and speech delays. In *Proceedings of the Designing Interactive Systems Conference on - DIS '12*. pp. 126–135. Available at: http://dl.acm.org/citation.cfm?doid=2317956.2317977.

Hailpern, J., Karahalios, K. & Special, J.H., 2009. Creating a Spoken Impact: Encouraging Vocalization through Audio Visual Feedback in Children with ASD. In *Proceedings of the SIGCHI conference on human factors in computing systems Apr 4 (pp. 453-462). ACM.* pp. 453–462.

Hall, C.M. & Bierman, K.L., 2015. Technology-assisted interventions for parents of young children: Emerging practices, current research, and future directions. *Early Childhood Research Quarterly*, 33, pp.21–32. Available at: http://dx.doi.org/10.1016/j.ecresq.2015.05.003.

Halskov, K. & Dalsgård, P., 2006. Inspiration Card Workshops. In *DIS'06 Proceedings of the 6th conference on Designing Interactive systems*. pp. 2–11.

Hamaguchi, P.M., 2010. *Childhood speech, language, and listening problems: What Every*

Parent Should Know Third Edit., John Wiley & Sons.

Hamidi, F. & Baljko, M., 2014. Rafigh: A Living Media Interface for Speech Intervention. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*. pp. 1817–1820.

Hart, B. & Risley, T., 1995. *Meaningful Differences in Everyday Experiences of Young American Children*,

Hartley, S.L. et al., 2010. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), pp.449–457.

Hastings, R.P. et al., 2005. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), pp.377–391.

Hayes, G.R. et al., 2008. CareLog: a selective archiving tool for behavior management in schools. In *Proceeding of the twenty-sixth annual CHI conference on Human factors in computing systems - CHI '08*. pp. 685–694. Available at: http://dl.acm.org/citation.cfm?id=1357054.1357164.

Hayes, G.R., 2006. Documenting and understanding everyday activities through the selective archiving of live experiences. In *CHI '06 extended abstracts on Human factors in computing systems - CHI '06*. p. 1759. Available at: http://portal.acm.org/citation.cfm?doid=1125451.1125782.

Hayes, G.R. et al., 2014. Estrellita: A Mobile Capture and Access Tool for the Support of Preterm Infants and Their Caregivers. *ACM Transactions on Computer-Human Interaction*, 21(3), pp.1–28. Available at: http://dl.acm.org/citation.cfm?id=2633906.2617574.

Hayes, G.R. et al., 2005. Experience buffers: a socially appropriate, selective archiving tool for evidence-based care. In *Proceedings of ACM CHI 2005 Conference on Human Factors in Computing Systems*. pp. 1435–1438. Available at: http://doi.acm.org/10.1145/1056808.1056935.

Hayes, G.R. et al., 2007. Physical, Social, and Experiential Knowledge in Pervasive Computing Environments. *the IEEE Computer Society - PERVASIVE computing*, 1836.

Hayes, G.R. et al., 2011. Supporting the transition from hospital to home for premature infants using integrated mobile computing and sensor support. *Personal and Ubiquitous Computing*, 15, pp.871–885.

Hayes, G.R., 2012. Taking action in your research. *Interactions*, 19(4), pp.50–3.

Hayes, G.R., 2011. The Relationship of Action Research to Human-Computer Interaction. *ACM Transactions on Computer-Human Interaction*, 18(3), pp.645–685.

Hayes, G.R. & Abowd, G.D., 2006. Tensions in designing capture technologies for an evidence-based care community. In *Proceedings of the SIGCHI conference on Human Factors in computing systems - CHI '06*. p. 937. Available at: http://portal.acm.org/citation.cfm?doid=1124772.1124911.

Hayes, G.R. & Truong, K.N., 2009. Selective Archiving: A Model for Privacy Sensitive Capture and Access Technologies. In *Protecting Privacy in Video Surveillance*. Springer-Verlag London Limited, pp. 165–184.

HealthGrades Inc, 2018. Statistics by Country for Cerebral Palsy. *HealthGrades*. Available at: http://www.rightdiagnosis.com/c/cerebral_palsy/stats-country.htm [Accessed September 19, 2018].

Hecht, J. et al., 2005. Motivational interviewing in community-based research: experiences from the field. *Annals of Behavioral Medicine*, 29(2), pp.29–34.

Higgins, D.J., Bailey, S.R. & Pearce, J.C., 2005. Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), pp.125–137.

Hines, M. et al., 2015. Speech pathologists' perspectives on transitioning to telepractice: What factors promote acceptance? *Journal of Telemedicine and Telecare*, 0(0), pp.1–5. Available at: http://jtt.sagepub.com/lookup/doi/10.1177/1357633X15604555.

Hinojosa, J., 1990. How Mothers of Preschool Children With Cerebral Palsy Perceive Occupational and Physical Therapists and Their Influence on Family Life. *The Occupational Therapy Journal of Research: Occupation, Participation and Health*, 10(3), pp.144–162.

Hinojosa, J. & Anderson, J., 1991. Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *The American Journal of Occupational Therapy*, 45(3), pp.273–279.

Hodges, S., Berry, E. & Wood, K., 2011. SenseCam: A wearable camera that stimulates and rehabilitates autobiographical memory. *Memory*, 19(7), pp.685–696.

Hoque, M.E. et al., 2009. Exploring speech therapy games with children on the autism spectrum. In *Proceedings of the 10th Annual Conference of the International Speech Communication Association*. pp. 1455–1458. Available at: http://dspace.mit.edu/handle/1721.1/56580%5Cnhttp://hdl.handle.net/1721.1/56580.

Hornby, G., 2000. *Improving Parental Involvement*, A&C Black.

Houde, S. & Hill, C., 1997. What do prototypes prototype? In *In Handbook of Human-Computer Interaction (Second Edition)*. pp. 367–381.

Huh, J. et al., 2014. Health Vlogs as Social Support for Chronic Illness Management. *ACM Transactions on Computer-Human Interaction*, 21(4), pp.1–31. Available at: http://dl.acm.org/citation.cfm?doid=2633907.2630067.

Hustad, K. et al., 2012. Intelligibility of 4-Year-Old Children With and Without Cerebral Palsy. *Journal of Speech, Language, and Hearing Research*, 55, pp.1177–1189.

Hwang, I. et al., 2014. TalkBetter: Family-driven Mobile Intervention Care for Children with Language Delay. In *Proceedings of the 17th ACM conference on Computer supported cooperative work & social computing - CSCW '14*. pp. 1283–1296. Available at: http://dl.acm.org/citation.cfm?id=2531602.2531668.

Ingersoll, B. et al., 2016. Comparison of a Self-Directed and Therapist-Assisted Telehealth Parent-Mediated Intervention for Children with ASD: A Pilot RCT. *Journal of Autism and Developmental Disorders*, 46(7), pp.2275–2284.

Ingersoll, B. & Berger, N.I., 2015. Parent engagement with a telehealth-based parent-mediated intervention program for children with autism spectrum disorders: Predictors of program use and parent outcomes. *Journal of Medical Internet Research*, 17(10).

Isaki, E. & Farrell, C.F., 2015. Provision of Speech-Language Pathology Telepractice Services Using Apple iPads. *Telemedicine and e-Health*, 21(7), pp.538–549. Available at: http://online.liebertpub.com/doi/10.1089/tmj.2014.0153.

Jones, S., 2004. Augmentative and alternative communication: Management of severe communication disorders in children and adults. *Journal of Applied Research in Intellectual Disabilities*, 17(2), pp.133–134.

Judge, S.L., 1998. Parental Coping Strategies and Strengths in Families of Young Children with Disabilities. *Family Relations*, 47(3), pp.263–268. Available at: http://www.jstor.org/stable/584976?origin=crossref.

Kamisafe, 2018. Kamisafe Octopus Flexible Tripod. Available at: https://www.amazon.co.uk/Kamisafe-KINGJOY-Adjustable-Flexible-Cellphones/dp/B01JRO45RI.

Karnieli-Miller, O., Strier, R. & Pessach, L., 2008. Power Relations in Qualitative Research. *Qualitative Health Research*, 19(2), pp.279–289.

Kavussanu, M. et al., 2008. Coaching Efficacy and Coaching Effectiveness: Examining Their Predictors and Comparing Coaches' and Athletes' Reports. *The Sport Psychologist*, 22(4), pp.383–404. Available at: http://journals.humankinetics.com/doi/10.1123/tsp.22.4.383.

Kazdin, A.E., 1977. Artifact, bias, and complexity of assessment: The ABCs of reliability.

Journal of Applied Behavior Analysis, 10, pp.41–150.

Kazdin, A.E., 1982. Observer effects: Reactivity of direct observation. *New Directions for Methodology of Social & Behavioral Science*, 14, pp.5–19.

Kearney, P.M. & Griffin, T., 2001. Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), pp.582–592.

Keck, C.S. & Doarn, C.R., 2014. Telehealth technology applications in speech-language pathology. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association*, 20(7), pp.653–9. Available at: http://www.ncbi.nlm.nih.gov/pubmed/24820794.

Kelso, G.L. et al., 2009. The Feasibility of Virtual Home Visits to Provide Early Intervention. *Infants & Young Children*, 22(4), pp.332–340.

Kennedy, H., Landor, M. & Todd, L., 2011. *Video Interaction Guidance: A relationship-based intervention to promote attunement, empathy and wellbeing*, Jessica Kingsley Publishers.

Kientz, J.A. et al., 2005. Abaris: Evaluating Automated Capture Applied to Structured Autism Interventions. In *International Conference on Ubiquitous Computing*. pp. 323–339.

Kientz, J.A. et al., 2006. From the war room to the living room: decision support for home-based therapy teams. In *Proceedings of the 2006 20th anniversary conference on Computer supported cooperative work*. pp. 209–218. Available at: http://portal.acm.org/citation.cfm?doid=1180875.1180909.

Kientz, J.A., Arriaga, R.I., et al., 2007. Grow and Know: Understanding Record-Keeping Needs for Tracking the Development of Young Children. In *Proceedings of the ACM 2007 Conference on Human Factors in Computing Systems*. pp. 1351–1360.

Kientz, J.A., Hayes, G.R., et al., 2007. Pervasive Computing and Autism: Assisting Caregivers of Children with Special Needs. *IEEE Pervasive Computing*, 6.

Kientz, J.A. et al., 2008. The Georgia Tech aware home. In *Proceeding of the twenty-sixth annual CHI conference extended abstracts on Human factors in computing systems - CHI '08*. p. 3675. Available at: http://portal.acm.org/citation.cfm?doid=1358628.1358911.

Kientz, J.A. & Abowd, G.D., 2009. KidCam: Toward an effective technology for the capture of children,s moments of interest. *Pervasive 2009, LNCS 5538*, 5538 LNCS, pp.115–132.

Kientz, J.A., Arriaga, R.I. & Abowd, G.D., 2009. Baby steps: Evaluation of a system to support record- keeping for parents of young children. In *Conference on Human Factors*

in Computing Systems - Proceedings. pp. 1713–1722. Available at: http://www.scopus.com/inward/record.url?eid=2-s2.0-84892450574&partnerID=40&md5=ac66cb1e31b8c9d53185dde6763ef236.

Kindberg, T. et al., 2005. I Saw This and Thought of You: Some Social Uses of Camera Phones. In *CHI '05 extended abstracts on Human factors in computing systems - CHI '05*. p. 1545. Available at: http://dl.acm.org/citation.cfm?id=1056808.1056962.

King, S. et al., 2004. Family-Centered Service for Children with Cerebral Palsy and Their Families: A Review of the Literature. *Seminars in Pediatric Neurology*, 11(1), pp.78–86.

Kivlighan, D.M.J. & Shaughnessy, P., 1995. An analysis of the development of the working alliance using hierarchical linear modeling. *Journal of Counseling Psychology*, 42(3), pp.338–349.

Kollenburg, J. van et al., 2018. Exploring the Value of Parent Tracked Baby Data in Interactions with Healthcare Professionals. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*. pp. 1–12. Available at: http://dl.acm.org/citation.cfm?doid=3173574.3173871.

Kretlow, A.G., Wood, C.L. & Cooke, N.L., 2011. Using in-service and coaching to increase kindergarten teachers' accurate delivery of group instructional units. *Journal of Special Education*, 44(4), pp.234–246.

Landsman, G., 2002. Emplotting children's lives: Developmental delay vs. disability. *Social Science and Medicine*, 56(9), pp.1947–1960.

Landsman, G., 1998. Reconstructing motherhood in the age of `perfect' babies: mothers of infants and toddlers with disabilities. *Signs: Journal of Women in Culture and Society*, 24, pp.69–99.

Law, J., Garrett, Z. & Nye, C., 2005. *Speech and Language Therapy Interventions for Children with Primary Speech and Language Delay or Disorder*, The Campbell Collaboration (C2).

Lee, J.-J., 2014. The True Benefits of Designing Design Methods. *Artifact*, 3(2), p.5.1-5.12.

Lehr, S. & Lehr, R., 1990. Getting what you want: expectations of families. *Quality Assurance for Individuals with Developmental Disability: It's Everybody's Business*, pp.61–75.

Leiter, V. et al., 2004. The Consequences of Caring: Effects of Mothering a Child With Special Needs. *Journal of Family Issues*, 25(3), pp.379–403.

LENA, 2018. LENA. Available at: https://www.lena.org.

Leo, G. De et al., 2011. A Smart-Phone Application and a Companion Website for the

Improvement of the Communication Skills of Children with Autism: Clinical Rationale, Technical Development and Preliminary Results. *Journal of medical systems*, 35(4), p.703–711.

Leung, A.K. & Kao, C.P., 1999. Evaluation and Management of the Child with Speech Delay. *Am Fam Physician.* Available at: http://www.aafp.org/afp/1999/0601/p3121.html.

Li, I., Dey, A. & Forlizzi, J., 2010. A stage-based model of personal informatics systems. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10*. p. 557. Available at: http://portal.acm.org/citation.cfm?doid=1753326.1753409.

Light, A. & Akama, Y., 2012. The human touch: participatory practice and the role of facilitation in designing with communities. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1*. pp. 61–70.

Lim, Y. et al., 2006. Comparative Analysis of High- and Low-fidelity Prototypes for More Valid Usability Evaluations of Mobile Devices. In *In Proceedings of the 4th Nordic conference on Human-computer interaction: changing roles*. pp. 291–300.

Liu, L.S. et al., 2011. Improving communication and social support for caregivers of high-risk infants through mobile technologies. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work - CSCW '11*. p. 475. Available at: http://portal.acm.org/citation.cfm?doid=1958824.1958897.

Lloyd, D., 2012. *Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey*, London.

Locke, A., Ginsborg, J. & Peers, I., 2002. Development and disadvantage: implications for the early years and beyond. *International Journal of Language and Communication Disorders*, 1(37), p.315.

Lord, C. et al., 2005. Challenges in evaluating psychosocial interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 35(6), pp.695–708.

Lord, J., 1984. Cerebral palsy: A clinical approach. *Archives of Physical Medirine and Rehabilitation*, 65, pp.542–548.

Maas, E. et al., 2008. Principles of Motor Learning in Treatment of Motor Speech Disorders. *Am J Speech Lang Pathol*, 17(3), pp.277–98.

MacKintosh, V.H., Goin-Kochel, R.P. & Myers, B.J., 2012. "what do you like/dislike about the treatments you're currently using?": A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27(1), pp.51–60.

Majnemer, A., 1998. Benefits of early intervention for children with developmental disabilities. *Seminars in Pediatric Neurology*, 5(1), pp.62–69. Available at: http://www.sciencedirect.com/science/article/pii/S107190919880020X.

Mamykina, L. et al., 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. *Chi 2008: 26th Annual Chi Conference on Human Factors in Computing Systems Vols 1 and 2, Conference Proceedings*, pp.477–486.

Mann, S., 2004. 'People-work': emotion management, stress and coping. *British Journal of Guidance & Counselling*, 32(2), pp.205–221.

Manolson, H.A., 1979. PARENT TRAINING : A MEANS OF IMPLEMENTING PRAGMATICS IN EARLY LANGUAGE REMEDIATION. *HUMAN COMMUNICATION*, pp.275–281.

Manuel, J. et al., 2003. Stress and Adaptation in Mothers of Children With Cerebral Palsy. *Journal of Pediatric Psychology*, 28(3), pp.197–201. Available at: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc13a&NEWS=N&AN=2016-13532-017.

Marcu, G., Dey, A.K. & Kiesler, S., 2012. Parent-Driven Use of Wearable Cameras for Autism Support: A Field Study with Families. In *Proceedings of the 2012 ACM Conference on Ubiquitous Computing - UbiComp '12*. p. 401. Available at: http://dl.acm.org/citation.cfm?id=2370216.2370277%5Cnhttp://dl.acm.org.ezproxy.napier.ac.uk/citation.cfm?id=2370216.2370277.

Marcu, G. & Hayes, G.R., 2010. Use of a Wearable Recording Device in Therapeutic Interventions for Children with Autism. In *Workshop on Interactive Systems in Healthcare*. pp. 113–116. Available at: http://www.gillianhayes.com/wp-content/uploads/2011/01/23_WISHSenseCam_2010.pdf.

Marshall, K. et al., 2014. Making Wellbeing: A Process of User-Centered Design. *Proceedings of DIS 2014*, pp.755–764. Available at: http://di.ncl.ac.uk/publications/Marshall-et-al-MakingWellbeing.pdf.

Mattelmäk, i T., 2008. Probing for co-exploring. *CoDesign*, 4(1), pp.65–78.

Mayring, P., 2004. Qualitative Content Analysis in Flickr. In *A Companion to Qualitative Research*. Sage, London.

Mcduffie, A. et al., 2013. Distance Video-Teleconferencing in Early Intervention: Pilot Study of a Naturalistic Parent-Implemented Language Intervention. *Topics in Early Childhood Special Education*, 33(3), pp.172–185.

McFarland, B., 2018. Cerebral Palsy Organization in UK. *UK Cerebral Palsy Organization*.

Available at: http://www.cerebralpalsy.org.uk/ [Accessed September 19, 2018].

McGoron, L. & Ondersma, S.J., 2015. Reviewing the need for technological and other expansions of evidence-based parent training for young children. *Children and Youth Services Review*, 59, pp.71–83. Available at: http://dx.doi.org/10.1016/j.childyouth.2015.10.012.

McLaughlin, M., 2011. Speech and Language Delay in Children. *American Family Physician*, 83(10).

Meadan, H. & Daczewitz, M.E., 2015. Internet-based intervention training for parents of young children with disabilities: A promising service-delivery model. *Early Child Development and Care*, 185(1), pp.155–169. Available at: http://www.tandfonline.com/doi/abs/10.1080/03004430.2014.908866.

Mentis, H.M. et al., 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*.

Metzler, C.W. et al., 2012. Using consumer preference information to increase the reach and impact of media based parenting interventions in a public health approach to parenting support. *Behavior Therapy*, 43(2), pp.257–270.

Mody, M. & Belliveau, J.W., 2013. Speech and Language Impairments in Autism: Insights from Behavior and Neuroimaging. *North American journal of medicine & science*, 5(3), pp.157–161. Available at: http://www.ncbi.nlm.nih.gov/pubmed/24349628%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3862077.

Moody, L., 2015. User-Centred Health Design: Reflections on D4D's experiences and challenges. *Journal of medical engineering & technology*, 39(7), pp.395–403.

Muller, M., 2001. A participatory poster of participatory methods. In *CHI'01 extended abstracts on Human factors in computing systems*. pp. 99–100.

Muller, M.J., 2003. Participatory design: the third space in HCI. In *Human-computer interaction: Development process*. pp. 1051–1068.

Muller, M.J. & Druin, A., 2012. Participatory Design: The Third Space in HCI.pdf. In *The human-computer interaction handbook*. Lawrence Erlbaum, Hillsdale, pp. 1125–1154.

Muller, M.J., Haslwanter, J.H. & Dayton, T., 1997. Participatory Practices in the Software Lifecycle. In *Handbook of human-computer interaction*. pp. 255–297.

Nazneen, N., Rozga, A., et al., 2012. Supporting parents for in-home capture of problem behaviors of children with developmental disabilities. *Personal and Ubiquitous Computing*, 16(2), pp.193–207.

Nazneen, N., Boujarwah, F., et al., 2012. Towards in-home Collection of Behavior Specimens: Within the Cultural Context of autism in Pakistan. In *Proceedings of the 6th International Conference on Pervasive Computing Technologies for Healthcare*. pp. 9–16. Available at: http://eudl.eu/doi/10.4108/icst.pervasivehealth.2012.248701.

Nese, R.N.T. et al., 2016. Effects of a video feedback parent training program during child welfare visitation. *Children and Youth Services Review*, 71, pp.266–276. Available at: http://dx.doi.org/10.1016/j.childyouth.2016.11.007.

Nguyen, D.H. et al., 2009. Encountering SenseCam: Personal Recording Technologies in Everyday Life. In *UbiComp*. p. 182. Available at: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.147.9295&rep=rep1&type=pdf%5Cnhttp://portal.acm.org/citation.cfm?doid=1409635.1409661.

NHS, 2019. Birth to five development timeline. Available at: https://www.nhs.uk/tools/documents/timelines_js/index.html?project=birth_to_five.

Niela-Vilén, H. et al., 2014. Internet-based peer support for parents: A systematic integrative review. *International Journal of Nursing Studies*, 51(11), pp.1524–1537.

Nieuwboer, C.C., Fukkink, R.G. & Hermanns, J.M.A., 2013. Online programs as tools to improve parenting: A meta-analytic review. *Children and Youth Services Review*, 35(11), pp.1823–1829. Available at: http://dx.doi.org/10.1016/j.childyouth.2013.08.008.

Oelofsen, N. & Richardson, P., 2006. Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31(1), pp.1–12.

Olsen, J., 2014. Health Coaching: A Concept Analysis. *Nursing Forum*, 49(1), pp.18–29.

Ones, K. et al., 2005. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair*, 19(3), pp.232–237.

ØSTENSJØ, S., CARLBERG, E.B. & VØLLESTAD, N.K., 2005. The use and impact of assistive devices and other environmental modifications on everyday activities and care in young children with cerebral palsy. *Disability and Rehabilitation*, 27(14), pp.849–861.

Owen, R., Hayett, L. & Roulstone, S., 2004. Children's views of speech and language therapy in school: Consulting children with communication difficulties. *Child Language Teaching and Therapy*, 20(1), pp.55–73.

Palen, L., 2010. Better ODDS than "Snowballs in Hell?"–or–What might action research do for HCI. *In Proceedings of the Human-Computer Interaction Consortium*.

Park, S.Y., Jeong, H.Y. & Zimmerman, J., 2008. ENSURE: Support for Parents in Managing their Children's Health. In *Proceedings of the Conference on Design and Emotion*.

Passmore, J., Peterson, D. & Freire, T., 2013. *The Wiley-Blackwell Handbook of the Psychology of Coaching and Mentoring*, John Wiley & Sons.

Patel, S.N. & Abowd, G.D., 2004. The ContextCam : Automated Point of Capture Video Annotation. In *Proceedings of The International Conference on Ubiquitous Computing (UbiComp '04)*. pp. 301–318.

Pennington, L. et al., 2009. Effects of It Takes Two to Talk- The Hanen Program for Parents of Preschool Children With Cerebral Palsy: Findings From an Exploratory Study. *J Speech Lang Hear Res*, 52(5), pp.1121–38.

Pennington, L., Goldbart, J. & Marshall, J., 2004. Interaction training for conversational partners of children with cerebral palsy: a systematic review. *International journal of language & communication disorders / Royal College of Speech & Language Therapists*, 39(2), pp.151–170.

Pennington, L., Goldbart, J. & Marshall, J., 2003. Speech and language therapy to improve the communication skills of children with cerebral palsy. *The Cochrane Database of Systematic Reviews*.

Pennington, L., Laws, K. & Goldbart, J., 2017. Parent-mediated communication interventions for improving the communication skills of preschool children with non-progressive motor disorders. *Cochrane Database of Systematic Reviews*, 2017(1).

Pennington, L. & McConachie, H., 2001. Predicting patterns of interaction between children with cerebral palsy and their mothers. *Developmental Medicine and Child Neurology*, 43(2), pp.83–90.

Pepper, J. & Weitzman, E., 2004. *It Takes Two to Talk: A Practical Guide For Parents of Children With Language Delays*, Hanen Centre Publication.

Peterson, P., Carta, J.J. & Greenwood, C., 2005. Teaching enhanced milieu language teaching skills to parents in multiple risk families. *Journal of Early Intervention*, 27(2), pp.94–109.

Pickard, K.E. et al., 2016. A mixed-method evaluation of the feasibility and acceptability of a telehealth-based parent-mediated intervention for children with autism spectrum disorder. *Autism*, 20(7), pp.845 –855.

Pickles, A. et al., 2016. Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet*, 388(10059), pp.2501–2509. Available at: http://dx.doi.org/10.1016/S0140-6736(16)31229-6.

Pina, L. et al., 2014. In Situ Cues for ADHD Parenting Strategies Using Mobile Technology.

In *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare*. pp. 17–24. Available at: http://eudl.eu/doi/10.4108/icst.pervasivehealth.2014.254958.

Piotrowska, P.J. et al., 2017. Mothers, Fathers, and Parental Systems: A Conceptual Model of Parental Engagement in Programmes for Child Mental Health—Connect, Attend, Participate, Enact (CAPE). *Clinical Child and Family Psychology Review*, 20(2), pp.146–161.

Prewett, M.S. et al., 2012. A meta-analysis of vibrotactile and visual information displays for improving task performance. *IEEE Transactions on Systems, Man, and Cybernetics, Part C (Applications and Reviews)*, 42(1), pp.123–132.

Pykhtina, O. et al., 2012a. Magic Land: Play Therapy on Interactive Tabletops. In *Proceedings of CHI'12*. p. 136. Available at: http://dl.acm.org/citation.cfm?id=2317956.2317978.

Pykhtina, O. et al., 2012b. Magic Land: The Design and Evaluation of an Interactive Tabletop Supporting Therapeutic Play with Children. In *DIS 2012*. pp. 517–524.

Raina, P. et al., 2005. The Health and Well-Being of Caregivers of Children With Cerebral Palsy. *PEDIATRICS*, 115(6), pp.626–636.

Redman-bentley, D., 1982. Parent expectations for professionals providing services to their handicapped children. *Physical & Occupational Therapy In Pediatrics*, 2(1), pp.13–28.

Rijn, H. van & Stappers, P., 2008. Expressions of ownership: motivating users in a co-design process. *PDC '08 Proceedings of the Tenth Anniversary Conference on Participatory Design*, pp.178–181. Available at: http://dl.acm.org/citation.cfm?id=1795266.

Robertsa, M.Y. & Kaiser, A.P., 2011. The Effectiveness of Parent-Implemented Language Interventions: A Meta-Analysis. *American Journal of Speech-Language Pathology*, 20, pp.180–199.

Rogers, S.J. & Vismara, L.A., 2008. Evidence-Based Comprehensive Treatments for Early Autism. *Journal of Clinical Child & Adolescent Psychology*, 37(1), pp.8–38.

Rosenbaum, P. et al., 2007. A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology*, 49(SUPPL.109), pp.8–14.

Roulstone, S. et al., 2010. *Investigating the role of language in children's early educational outcomes*, UK Department of Education.

Roulstone, S. et al., 2011. *The role of language in children's early educational outcomes*,

Ruch, G., 2005. Relationship-based practice and reflective practice: holistic approaches to contemporary child care social work. *Child & Family Social Work,*, 10(2), p.Child &

Family Social Work.

Rush, D., Shelden, M. & Hanft, B., 2003. Coaching families and colleagues: A process for collaboration in natural settings. *Infants & Young Children*, 16(1), pp.33–47.

Sanders, E., Brandt, E. & Binder, T., 2010. A Framework for Organizing the Tools and Techniques of Participatory Design. In *PDC 2010 - Proceedings of the 11th Biennial Participatory Design Conference*. pp. 195–198.

Sanders, M.R. et al., 2014. A comparison of online versus workbook delivery of a self-help positive parenting program. *Journal of Primary Prevention*, 35(3), pp.125–133.

Sangiorgi, D., 2011. Transformative services and transformation design. *International Journal of Design*, 5(1), pp.29–40.

Sarkar, M. et al., 2016. Psychosocial Health, e-Health Literacy, and Perceptions of e-Health as Predictors and Moderators of e-Health Use Among Caregivers of Children with Special Healthcare Needs. *Telemedicine and e-Health*, 22(2), p.150821140505001. Available at: http://online.liebertpub.com/doi/10.1089/tmj.2015.0028.

Schmidt, R.A. & Lee, T.D., 2005. *Motor Control and Learning: A Behavioral Emphasis* 4th ed., Leeds: Human Kinetics Europe Ltd.

Schorch, M. et al., 2016. Designing for Those who are Overlooked - Insider Perspectives on Care Practices and Cooperative Work of Elderly Informal Caregivers. *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16*, pp.785–797. Available at: http://dl.acm.org/citation.cfm?doid=2818048.2819999.

Schrader-McMillan, A., Barnes, J. & Barlow, J., 2012. *Primary study evidence on effectiveness of interventions (home, early education, child care) in promoting social and emotional wellbeing of vulnerable children under 5*,

Schwartz, S. & Miller, J.E.H., 1996. *The New Language of Toys: Teaching Communication Skills to Children with Special Needs: a Guide for Parents and Teachers*, Woodbine House.

Sellen, A.J. et al., 2007. Do life-logging technologies support memory for the past? In *Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '07*. pp. 81–90. Available at: http://portal.acm.org/citation.cfm?doid=1240624.1240636.

Sen, E. & Yurtsever, S., 2007. Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing*, 12(4), pp.238–252. Available at: http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L476310 27%5Cnhttp://dx.doi.org/10.1111/j.1744-

6155.2007.00119.x%5Cnhttp://openurl.ac.uk/ukfed:bath.ac.uk?sid=EMBASE&issn=15390136&id=doi:10.1111/j.1744-6155.2007.00119.x&atitle=Diffi.

Shong, S. & Cheng, S., 2007. Language Assessment: A Review Of Cross-Cultural Issues, And The Development Of An Indigenous Tool For Hong Kong Infants And Toddlers. In *Educational Psychology Research Focus*. p. 191.

Simard, L. et al., 2014. *Early Childhood Development*, Available at: http://www.worldbank.org/content/dam/Worldbank/Publications/WDR/WDR 2015/Chapter-5.pdf.

Simonsen, J. & Robertson, T., 2013. *Routledge International Handbook of Participatory Design*, Routledge.

Snodgrass, M.R. et al., 2017. Telepractice in Speech-Language Therapy: The Use of Online Technologies for Parent Training and Coaching. *Communication Disorders Quarterly*, 38(4), pp.242–254. Available at: http://cdq.sagepub.com/cgi/doi/10.1177/1525740116680424.

Solish, A. & Perry, A., 2008. Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders*, 2(4), pp.728–738.

Solomon, A.H. & Chung, B., 2012. Understanding Autism: How Family Therapists Can Support Parents of Children with Autism Spectrum Disorders. *Family Process*, 51(2), pp.250–264.

Sparks, 2018. SPARKS - Children's Medical Research. *Sparks Charity*. Available at: http://www.sparks.org.uk/.

Spinuzzi, C., 2005. The Methodology of Participatory Design. *Technical Communication*, 52(2), pp.163–174. Available at: http://www.ingentaconnect.com/content/stc/tc/2005/00000052/00000002/art00005.

Steen, M., 2013. Co-Design as a Process of Joint Inquiry and Imagination. *Design Issues*, 29(2), pp.16–28.

Steen, M., Manschot, M. & Koning, N. De, 2011. Benefits of Co-design in Service Design Projects. *International Journal of Design*, 5(2), pp.53–61.

Stern, K., 2018. Prevalence of Cerebral Palsy. *MyChild at CerebralPalsy.org*. Available at: http://www.cerebralpalsy.org/about-cerebral-palsy/prevalence-and-incidence [Accessed September 20, 2018].

Stern, L. et al., 1995. The Adelaide preschool language unit - Results of follow up. *Journal of Paediatrics and Child Health*, 31(3), pp.207–212.

Stokes, J. & Cummins, K., 2013. Video Use in Reflective Practice: Experience from Educating Speech and Language Therapist. *The Journal of Learning and Teaching at the University of Greenwich*, (7), pp.1–7.

Suess, A.N. et al., 2014. Evaluating the Treatment Fidelity of Parents Who Conduct In-Home Functional Communication Training with Coaching via Telehealth. *Journal of Behavioral Education*, 23(1), pp.34–59.

Suh, H. et al., 2014. @BabySteps: Design and Evaluation of a System for using Twitter for Tracking Children's Developmental Milestones. *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14*, pp.2279–2288. Available at: http://dl.acm.org/citation.cfm?doid=2556288.2557386.

Sussman, F., 1999. *More Than Words: Helping parents promote communication and social skills in children with autism spectrum disorder*, Hanen Centre Publication.

Syrmpas, I. & Bekiari, A., 2018. Differences between leadership style and verbal aggressiveness profile of coaches and the satisfaction and goal orientation of young athletes. *Journal of Physical Education and Sport*, 18(2), pp.1008–1015.

Taanila, A. et al., 2002. Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28(1), pp.73–86.

Tang, K.P. et al., 2011. *Addressing the design challenges for a clinically-informed data capture tool targeted for caregivers of premature infants*,

Tang, K.P. et al., 2012. Balancing Caregiver and Clinician Needs in a Mobile Health Informatics Tool for Preterm Infants. In *Proceedings of the 2012 Pervasive Health Conference*.

Taylor, O.D. et al., 2014. A review of the efficacy and effectiveness of using telehealth for paediatric speech and language assessment. *Journal of Telemedicine and Telecare*, 20(7), pp.405–412.

Tomblin, J.B. et al., 1997. Prevalence of Specific Language Impairment in Kindergarten Children. *Journal of Speech, Language and Hearing Research*, (40), pp.1245–60. Available at: http://jslhr.asha.org/cgi/content/abstract/40/6/1245.

Tomitsch, M. et al., 2018. *Design. Think. Make. Break. Repeat. A handbook of methods*, BIS publishers.

Trivette, C.M., Dunst, C.J. & Hamby, D.W., 2010. Influences of Family-Systems Intervention Practices on Parent-Child Interactions and Child Development. *Topics in Early Childhood Special Education*, 30(1), pp.3–19.

Tse, Y.J. et al., 2015. Teletherapy Delivery of Caregiver Behavior Training for Children with

Attention-Deficit Hyperactivity Disorder. *Telemedicine and e-Health*, 21(6), pp.451–458. Available at: http://online.liebertpub.com/doi/10.1089/tmj.2014.0132.

Tully, L.A. et al., 2017. Optimizing child outcomes from parenting interventions: Fathers' experiences, preferences and barriers to participation. *BMC Public Health*, 17(1), p.550.

Ulgado, R. et al., 2013. VidCoach: A Mobile Video Modeling System for Youth with Special Needs. In *Proceedings of the 12th International Conference on Interaction Design and Children - IDC '13*. pp. 581–584. Available at: http://dl.acm.org/citation.cfm?id=2485760.2485870.

Vines, J. et al., 2013. Configuring participation: on how we involve people in design. In *Proceedings of CHI 2013*. pp. 429–438. Available at: http://dl.acm.org/citation.cfm?id=2470716%5Cnhttp://di.ncl.ac.uk/publications/ConfigPart_ACMArchiveCameraOptimised.pdf.

Vismara, L.A. et al., 2013. Preliminary findings of a telehealth approach to parent training in Autism. *Journal of Autism and Developmental Disorders*, 43(12), pp.2953–2969.

Vismara, L.A., Young, G.S. & Rogers, S.J., 2012. Telehealth for Expanding the Reach of Early Autism Training to Parents. *Autism Research and Treatment*, 2012, pp.1–12. Available at: http://www.hindawi.com/journals/aurt/2012/121878/.

Vonach, E. et al., 2016. Design of a Health Monitoring Toy for Children. In *Proceedings of the The 15th International Conference on Interaction Design and Children - IDC '16*. pp. 58–67. Available at: http://dl.acm.org/citation.cfm?doid=2930674.2930694.

Voorman, J.M. et al., 2009. Social functioning and communication in children with cerebral palsy: Association with disease characteristics and personal and environmental factors. *Developmental Medicine and Child Neurology*, 52(5), pp.441–447.

Wacker, D.P. et al., 2013. Conducting Functional Communication Training via Telehealth to Reduce the Problem Behavior of Young Children with Autism. *Journal of Developmental and Physical Disabilities*, 25(1), pp.35–48.

Wadhwa, B. & Jianxiong, C.C., 2013. Collaborative tablet applications to enhance language skills of children with autism spectrum disorder. In *Proceedings of the 11th Asia Pacific Conference on Computer Human Interaction - APCHI '13*. pp. 39–44. Available at: http://dl.acm.org/citation.cfm?doid=2525194.2525297.

Wainer, A.L. & Ingersoll, B.R., 2015. Increasing Access to an ASD Imitation Intervention Via a Telehealth Parent Training Program. *Journal of Autism and Developmental Disorders*, 45(12), pp.3877–3890. Available at: http://dx.doi.org/10.1007/s10803-014-2186-7.

Waite, M.C. et al., 2012. Assessing children's speech intelligibility and oral structures, and functions via an Internet-based telehealth system. *Journal of Telemedicine and Telecare*, 18, pp.198–203.

Wallace, J., Wright, P.C., et al., 2013. A design-led inquiry into personhood in dementia. *Proceedings of CHI 2013*, pp.2617–2626. Available at: http://dl.acm.org/citation.cfm?id=2481363%5Cnpapers://c80d98e4-9a96-4487-8d06-8e1acc780d86/Paper/p10660.

Wallace, J., McCarthy, J., et al., 2013. Making design probes work. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*. pp. 3441–3450. Available at: http://dl.acm.org/citation.cfm?doid=2470654.2466473.

Warren, Z. et al., 2011. A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders. *PEDIATRICS*, 127(5).

Watson, R.M. & Pennington, L., 2015. Assessment and management of the communication difficulties of children with cerebral palsy: a UK survey of SLT practice. *International Journal of Language & Communication Disorders*, 50(2), pp.241–259. Available at: 10.1111/1460-6984.12138%5Cnhttp://search.ebscohost.com/login.aspx?direct=true&db=buh&AN=101349418&site=ehost-live.

Whitley, E.A., 2009. Informational privacy, consent and the "control" of personal data. *Information security technical report*, 14(3), pp.154–159.

Wolever, R.Q. & Eisenberg, D.M., 2011. What Is Health Coaching Anyway?Standards Needed to Enable Rigorous Research. *Archives of internal medicine*, 171(22), pp.2017–2018.

Woodgate, R.L., Ateah, C. & Secco, L., 2008. Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism. *Qualitative health research*, 18(8), pp.1075–1083.

Wright, P. & McCarthy, J., 2008. Empathy and experience in HCI. In *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. p. 637–646).

Wright, P. & McCarthy, J., 2010. *Experience-centered design: designers, users, and communities in dialogue*, Morgan & Claypool Publishers.

Wright, P. & McCarthy, J., 2010. Experience-Centered Design: Designers, Users, and Communities in Dialogue. *Synthesis Lectures on Human-Centered Informatics*, 3(1), pp.1–23.

Yantzi, N.M., Rosenberg, M.W. & McKeever, P., 2007. Getting out of the house: The

challenges mothers face when their children have long-term care needs. *Health and Social Care in the Community*, 15(1), pp.45–55.

Yardley, L., 2000. Dilemmas in qualitative health research. *Psychology and Health*, 15(2), pp.215–228.

Yarosh, S. et al., 2016. "Best of Both Worlds": Opportunities for Technology in Cross-Cultural Parenting. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, pp.635–647. Available at: http://doi.acm.org/10.1145/2858036.2858210.