

**Feasibility of communication training for parents of preschool children with motor disorders with  
remote coaching using smartphone apps**

**Katy Stockwell<sup>1</sup>, Ebtisam Alabdulqader<sup>2</sup>, Dan Jackson<sup>2</sup>, Anna Basu<sup>1</sup>, Patrick Olivier<sup>2</sup>,**

**Lindsay Pennington<sup>1\*</sup>**

1. Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

2. Open Lab, Newcastle University, Newcastle upon Tyne, UK

\* Corresponding author: Lindsay Pennington, Institute of Health and Society, Newcastle University, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle Upon Tyne, UK.

NE1 4LP. Email: [lindsay.pennington@ncl.ac.uk](mailto:lindsay.pennington@ncl.ac.uk). Tel: 00 44 191 282 1360

**Abstract:**

**Background:** Communication training for parents of young children with neurodisability is often delivered in groups and includes video coaching. Group teaching is problematic when there is wide variation in characteristics and needs amongst participants.

**Aims:** To assess the potential feasibility and acceptability of delivering one-to-one parent training supported by remote coaching using smartphone apps and of conducting further trials of the intervention.

**Methods and procedures:** We aimed to recruit eight children aged 12-48 months with motor disorders and communication difficulties and to provide families with individual parent training in six weekly home visits supplemented by remote coaching via smartphone apps. For outcome measurement, parents recorded their interaction with their child thrice weekly during baseline (three weeks), intervention, post-intervention (three weeks) follow-up (1 week). Measures comprised parent responsiveness and counts of children's communication and vocalisation.

Research design feasibility was measured through rates of recruitment, attrition, outcome measure completion and agreement between raters on outcome measurement. Intervention feasibility was assessed through the proportion of therapy sessions received, the number of videos and text messages shared using the apps in remote coaching, and message content. Parents were interviewed about the acceptability of the intervention and trial design.

Interviews were transcribed and analysed using inductive thematic analysis.

**Outcomes and Results:** Nine children were recruited over 16 weeks. All fitted the inclusion criteria. Four families withdrew from the study. Five families completed the intervention. No family submitted the target number of video recordings for outcome measurement. Inter-rater agreement was moderate for child communication ( $K=0.46$ ) and vocalisation ( $K=0.60$ ) and

high for RAACS ( $r_s$  0.96). Parents who completed the intervention reported positive experiences of the programme and remote coaching via the apps. Therapist messages via the app contained comments on parent and child behaviour and requests for parental reflection/action; parental messages contained reflections on children's communication.

**Conclusions and Implications:** The intervention and study design demanded high levels of parental involvement and was not suitable for all families. Recording shorter periods of interaction via mobile phones or using alternative methods of data collection may increase feasibility of outcome measurement.

Early communication intervention for children with severe motor impairment often involves training parents to provide frequent communication opportunities in play and daily interactions to stimulate communication development. Training has often been delivered to groups of parents, with additional one-to-one coaching, but groups can be logistically challenging for departments in which low numbers of children share similar characteristics at any one time. This research aimed to test the acceptability of one-to-one parent training and the feasibility of future trials of the intervention. As sharing video recordings via smartphones is common practice for many adults, we also sought to assess the acceptability of sharing and annotating videos for the purposes of remote coaching to support the one-to-one therapy sessions.

Children with motor disorders, such as those associated with cerebral palsy (CP), often have difficulties producing the movements required for speech and gestural communication (Parkes et al., 2010, Sigurdardottir and Vik, 2011, McFadd and Hustad, 2013, Nordberg et al., 2013, Lee et al., 2014, Coleman et al., 2015, Mei et al., 2016). As a result, their communication may be difficult to interpret and parents may structure interaction around the children's signals that are readily understandable (Dunst, 1985, Pennington and McConachie, 2001). Young children with motor disorders have been observed to miss their turn in conversation, fill their turns nonverbally, and use a restricted range of communicative behaviours (Girolametto, 1988, Dahlgren-Sandberg and Liliedahl, 2008, Pennington and McConachie, 1999). Such restricted interactions limit their opportunity to develop the full range of communicative functions needed for independent communication, to acquire the motor programmes for speech production and to learn language.

Early intervention seeks to maximize children's development by creating engaging and appropriately challenging learning opportunities. It is often delivered by parents, as the child's most frequent carer and play/communication partners (Eliasson et al., 2011,

Whittingham et al., 2011, Roberts and Kaiser, 2012, Basu, 2014). In the case of communication development, early intervention is underpinned by transactional theory, which posits that parents and children continuously adapt to each other's communication behaviours (Sameroff and Feise, 2000). For children with motor disorders, the aim of intervention is for children to become more active, independent communicators, who will take equal turns in conversation with their parents, start interactions, respond contingently to their parents' communication, and use their turns for a wide range of communicative purposes (e.g. to ask questions and make comments rather than indicating yes or no). To achieve this, parents are taught strategies such as observing their child closely to identify communication behaviours, following their child's focus of attention, letting children take the lead in interaction, giving children time to communicate, responding contingently, and adding language to interactions to help children develop linguistic understanding and use words in conversation (Girolametto, 1988, Girolametto et al., 1998, Mahoney and Bella, 1998, Roberts and Kaiser, 2012). Parent training programmes have been shown to be effective in changing parents' behaviour towards children with motor disorders, reducing the directiveness of their communication and increasing their responsiveness to their children's communicative requests (Girolametto et al., 1998, Pennington et al., 2009, Kim and Mahoney, 2005) and increasing children's involvement in interaction, through more frequent communicative acts, and use of a wider range of communicative functions (Girolametto, 1988, Pennington et al., 2009).

Parent training programmes employ a range of validated methods to teach interaction strategies (Dunst and Trivette, 2009), including didactic presentations, group discussion, role play, instructional video and problem solving tasks. Parents are encouraged to apply their new knowledge in real life interaction with their children. In home visits parents are coached by therapists, who provide supportive feedback on parental application of communication

strategies and encourage parents to reflect on the effects of their behaviour on their children's communication (Hargreaves and Dawe, 1990). Coaching can involve live or video-recorded parent-child interaction (Pennington and Noble, 2010).

In our previous research we encountered two logistical difficulties for running parent communication groups for children with motor disorders in UK NHS Trusts. Firstly, families and therapists felt that groups worked best when parents had shared developmental concerns and children had similar communication patterns, but groups were difficult to schedule in departments where few children shared similar developmental characteristics (Pennington and Noble, 2010, Pennington and Thomson, 2007). One-to-one training for parents has been trialled in the US (Roberts and Kaiser, 2012), but research is needed to assess its acceptability and effectiveness for UK families served by the NHS. Secondly, video equipment was bulky and obtrusive for filming parent-child interaction. Video is now easy to capture using smartphones. Over 89% of UK adults aged 18-54 years now use smartphones (Deloitte, 2018) and parents' and fellow clinicians' had begun to report parents sharing smartphone video recordings to show clinicians examples of their children's behaviour. We questioned whether smartphones could be used in coaching parents to promote their child's communication development.

Mobile phones have already been used with some success in parent communication interventions with children at risk of language delay. Carta and colleagues (Carta et al., 2013) compared wait list control with one-to-one parent training and one-to-one parent training enhanced by text message support for mothers in low income families in a randomised controlled trial (RCT). Text message support comprised up to five text messages a week from trainers reminding mothers to use strategies taught in the one-to-one sessions. Mothers who received parent training with text message support used the strategies to encourage child interaction more often than mothers in the standard training group and mothers in a wait list

control group. They also experienced greater reductions in depression and stress. Sissel and colleagues (Sissel et al., 2015) also worked with mothers from low income families. In their RCT, mothers of children aged 2-30 months were allocated to either a wait list control or to receive audio advice on stimulating their children's communication delivered via a smartphone app. Messages were short (30-45 seconds) and included topics to talk about, providing a rich vocabulary, songs and rhymes. At follow-up, mothers who received audio advice spoke to their children more often than mothers in the control group and their children's language development gains exceeded those of the children in the control group. In both studies, the therapist took the role of the didactic expert and the parent was placed in the passive learner role. While both projects realised the potential of using mobile phones to engage parents, there was little partnership occurring outside of sessions, which may limit carry-over to naturally occurring, idiosyncratic interaction. It remains to be seen if the dialogue involving feedback and response and questions and answers, which naturally occurs during face-to-face coaching, can be facilitated through smartphone apps.

In a programme of research we set out to test if the strategies learned in group training could be taught in one-to-one training and if this model of intervention delivery was acceptable to parents. We also sought to explore the possibility of enhancing intervention by remote coaching via smartphones. We co-designed two apps with parents and speech and language therapists to video record interaction (KeepCam) and annotate the interaction with text messages (Relate) (Alabdulqader et al, submitted). The current study is the first stage in evaluating this complex intervention (Craig et al., 2008). Previous research has used single case experimental design (SCED) and group designs to evaluate parent training for families of children with severe disabilities (Parker-McGowan et al., 2014, Kent-Walsh et al., 2015, Pennington et al., 2018). Whereas group designs usually evaluate between and within group differences at discrete points in time (e.g. at one point before and one or two points after

intervention), SCED uses multiple measurements to observe the point at which behaviour change begins and how it proceeds. SCED is also a useful approach for populations with high heterogeneity and low prevalence (Schlosser and Raghavendra, 2003). We envisaged that SCED would allow us to investigate the variability in parents' and children's communication before, during and after intervention, and the rate of change for individuals, at least at the initial phases in the evaluation of the intervention. In this initial evaluation of the intervention we employed multiple measures at baseline, intervention, post-intervention and follow-up to assess the suitability of SCED for testing the intervention in the NHS. Our objectives for the study were to assess 1) the feasibility of future trial designs through rates of participant recruitment, participant attrition, the proportion of planned therapy sessions that were actually received by participants, the proportion of planned outcome measurements that were completed, and the reliability of outcome measure scoring; 2) the feasibility of using smartphone apps to support remote coaching by examining the frequency and types of messages produced by parents and their therapist; 3) the acceptability of the intervention and the trial design through semi-structured interviews with parents. The goal of the study was to determine if the intervention warranted further evaluation and to inform the design future trials (MRC, 2000, Craig et al., 2008, Bowen et al., 2009).

## **METHODS**

### Participants

We aimed to recruit eight families of preschool children who had a diagnosis of cerebral palsy or non-progressive motor disorder affecting gross motor movements and speech via speech and language therapists working in four UK NHS Trusts. We set broad inclusion criteria to reflect the heterogeneity of children with non-progressive motor disorders whose parents may be offered communication training in the UK NHS. Children were eligible for

inclusion if they were aged between 12 and 48 months, had a diagnosis of non-progressive motor disorder (e.g. cerebral palsy, CVA, cytomegalovirus), had oromotor disorders (as evidenced in reduced control over movements for eating, drinking, swallowing, saliva control and /or vocalisation/speech; as per clinical judgement) were able to vocalise and communicate with intent, and had no visual difficulties and hearing impairment less than 40dbHL. Frequency of child communication was not stipulated in the inclusion criteria. Families were excluded from the study if parents used a language other than English to communicate to their child (therapists providing the intervention were monolingual), parents were unable to read English (apps used text for remote coaching) or did not wish to use a smart phone to support therapy.

We used well-established measures to describe children's function to assess if they fitted the study criteria. The Gross Motor Function System (GMFCS) (Palisano et al., 1997) describes children's posture and mobility in a five level categorical scale from level I, which indicates ability to walk at indoors and outside, climb stairs without the use of a railing, and run and jump; to level V, which indicates that children are transported in a manual wheelchair in all settings and have limited ability to maintain antigravity head and trunk postures and control leg and arm movements). The Mini Manual Ability Classification System (MACS) describes children's use of their hands (Eliasson et al., 2017) and also uses a five point scale. At level I children handle objects easily and successfully; at level V children require total assistance, having severely limited ability to perform even simple actions. We used the visual receptive scale of the Mullen Scales of Early Learning (Mullen, 1995) to determine age equivalent nonverbal cognition. Language development was assessed using the Preschool Language Scale 4 (PLS4) (Zimmerman et al., 2002) and communication development was assessed using the Communication and Symbolic Behavior Scale (CSBS) (Wetherby and Prizant, 2002).

## Procedures

To examine the feasibility of using SCED in future trials, parents were asked to make three videos per week of their usual play or daily activities with their child from which communication change could be evaluated over four phases: three weeks' baseline, six weeks' intervention, three weeks' post-intervention and one week follow up at ten weeks post-intervention. This schedule was selected to provide sufficient data points from which to observe change in communication (Kratochwill et al., 2010). The study was approved by Newcastle and North Tyneside 1 Research Ethics Committee (15/NE/0221).

## *Equipment*

Parents were given a set of equipment at the start of the baseline, three weeks prior to intervention. 1) A gorilla stand for them to place their smartphone/camera where it could record the child, parent and environmental context in which interaction took place. 2) Two smartphone apps for remote coaching (described below). 3) A Bluetooth-enabled "selfie button" to remotely operate the apps. 4) A GoPro video camera. In the design phase of the research we had envisaged that smartphones would be used to record interaction for outcome measurement and for remote coaching in the intervention. However, to examine patterns of communication behaviour recordings of at least ten minutes were needed (Roberts and Kaiser, 2012, Pennington et al., 2018). The data generated in such recordings exceeded smartphone capacity and so GoPro cameras were used to record interaction for outcome measurement. 5) A soft Lycra waist belt with slot for an accelerometer. 6) A wallet containing the accelerometers and security disk (SD) cards needed for up to three weeks. SD cards and accelerometers were changed each week, at therapy visits.

We installed the two bespoke apps on parents' phones: KeepCam, captured looped video, and Relate, allowed captured video to be shared with the therapist and annotated with text. The

looping function in KeepCam allowed parents to record interactions just after they had seen a target behaviour. Parents were trained to set up the camera so that the parent, child and joint activity were all within the frame and to use the selfie button to activate video recording. The video loop was set at 50 seconds. This amount of time was chosen as parents would be able to capture strategy use, the environment and their child's communication with them. Parents could extend the recording frame by 40 seconds at a time, if needed, using the selfie button. The interface for Relate was similar to existing media-sharing apps in that it allowed parents to select a video from a folder in their smartphone photo library, add it to a message and then use text to annotate the video before sending it to the therapist. Initially, the two apps were to be integrated, but timing issues during development and difficulties integrating the KeepCam features into the Relate app meant the two apps were deployed.

### *Intervention*

The intervention taught parents evidence-based therapeutic techniques: being face to face with children; watching, waiting and listening; taking turns in play; adding language to play (Girolametto et al., 1998, Olswang et al., 1998, Sharry et al., 2005, Roberts and Kaiser, 2012). Intervention was provided by a research speech and language therapist in six once-weekly home visits, each lasting 50-70 minutes. Each session followed a common format: introduction or recap of a technique, including an explanation of how it could promote children's communication and role play of the technique; practice of the technique in triadic play with coaching; filming the parent practising the technique using KeepCam; discussion of the recorded interaction to highlight which behaviours prompted the child to engage in interaction; and planning for how the technique could be embedded in daily activities and play (Jennings et al., 2012, Friedman et al., 2012). Plans were recorded on a "communication toolbox" form to support understanding and recall (see Appendix). Coaching during the intervention sought to support parents to develop a reflective learning style where didactic

teaching from therapist is phased out, so that by the end of the intervention parents are more responsive to cues from their child (Hargreaves and Dawe, 1990, Woods et al., 2004, Brown and Woods, 2015). The coaching was informed by family guided routines based intervention, which defined coaching as a “set of flexible strategies that provide the provider and caregiver with opportunities to share information, learn and practice strategies, and solve problems in a manner guided by caregiver-identified priorities” (Friedman et al., 2012). All play in the therapy sessions used toys already in the family home.

As an example, the technique of being face to face with the child is described in a little more detail. The therapist explained that this would allow the child to see their parent’s whole face and expression, which would show that their parent is interested and ready to play and explained the communication of social cues with facial expression. The therapist and parent role played two different conversations, one with eye contact face to face and one without. Following the discussion of the strategy, the parents practiced being face to face with their child playing with one of the child’s favourite toys or in social play routines (e.g. pat-a-cake) and the therapist made video recordings of the interaction with KeepCam. The therapist and parent then watched the recording together and discussed what went well, with the therapist encouraging the parent to focus on the the things they did that prompted the child to engage in any way - body orientation towards parent, facial orientation, raising head to listen - even if behaviours were fleeting.

At the end of each session, parents were asked to use KeepCam to record their use of the strategies that were initially practiced in home visits and to annotate the video using Relate to show the behaviour they wanted to highlight to the therapist. Parents were asked to share these annotated videos with the therapist, who would then give feedback on the interactions and annotations using coaching techniques. No limit was set for the number of videos to be shared per week. The therapist replied to each video shared within 24 hours. Parents were

also encouraged to phone the therapist if any difficulties were experienced in using the apps so that we could trouble shoot their implementation. The second to sixth intervention sessions began with parental feedback on using the app throughout the week and trouble-shooting app deployment issues. Then, parents and therapists discussed the videos parents had shared in the preceding week and how parents had used the communication strategies taught in the intervention since the previous home visit.

## Measures

### *Intervention outcome measures*

Expected outcomes of the intervention are increases in parent responsiveness and increases in children's communication frequency, including vocal/verbal output (Girolametto, 1988, Girolametto et al., 1998, Mahoney and Bella, 1998, Roberts and Kaiser, 2012). Parental responsiveness was measured using The Responsive Augmentative and Alternative Communication Style scale (RAACS) (Broberg et al., 2012). Behaviours rated in RAACS relate directly to parent-interaction training and include the frequency with which parents attend to the child's focus of attention, observe their child and wait for communication, adjust their own position to be within the child's view and are visually engaged in interaction. The measure has been validated with parents of children who are nonverbal (Broberg et al., 2012). The frequency of children's communicative acts (defined as behaviours that are produced with the intent of influencing the parent's behaviour and to share meaning (Berko-Gleason, 2017) and the frequency of vocal or verbal communication (defined as the communicative acts expressed using voice or spoken language) were measured. Videos were coded by a research assistant who was blind to the intervention content and phase of the study. A second rater, also blind to the study phase and the first rater's coding, coded children's

communication and mothers' communication using RAACS from three randomly selected recordings from each family.

We hypothesised that changes in children's communication would be due to intervention, rather than maturation. We measured children's body movement videos using accelerometers as a control measure, expecting no change in gross motor behaviour (sitting, standing, moving around) during the study. The Gross Motor Function Measure (GMFM) (Russell et al., 2013) was used as an additional measure pre and post intervention, as the method of accelerometry data collection was un-tested for this population. Activities for the GMFM were carried out by the research speech and language therapist and then blind rated by a paediatric physiotherapist from videos of the assessment.

To enable us to measure outcomes, we asked parents to make three ten minute videos of their play with their child but did not specify where play should take place, which toys to play with or play routines to record. We also asked parents to activate the accelerometer just before the play, by shaking it in front of the camera, and then place it in the soft Lycra belt around the child's waist. At the end of the video the parents were asked to shake the accelerometer again to signal the end of the recording. The shaking was needed to match large accelerations with the date and time counter on the video recorder for movement analysis.

#### *Acceptability of the intervention and study design*

After the intervention and follow-up measures were complete, a research assistant who was not involved in intervention provision interviewed parents about the acceptability of the intervention and the study design. Topics covered included parents' experience of the therapy sessions (content, frequency, impact); experience of using the app (frequency of use, ease of use, fit with daily life); schedule of events for the research (e.g. videoing children; number of visits). The semi-structured format, with open questions such as "How did the therapy go?

How did you find it?” allowed topics to be raised in free-flowing conversation rather than a fixed question and answer format. Interviews were conducted in families’ homes and lasted 45 minutes to an hour. All interviews were audio recorded and transcribed verbatim.

#### *Measuring feasibility of study design*

To assess the feasibility of study design we used counts of the number of families identified by therapists who were willing to be contacted about the study; the rate of recruitment (number of families/ week); the number of families who consented to join the study; the number of families who completed the study (received intervention and completed outcome measures); the number of families who completed baseline measures; the number of therapy sessions each family received; the number of recordings that were made by families at each phase in the study (baseline, intervention, post therapy and follow-up); the number of video recordings that were analysable (both parent and child clearly visible and audible); the number of accelerometry data files that contained clear recordings of high velocity movements at the start and end of video recordings; and the inter-rater reliability of RAACS measurement.

#### *Measuring feasibility of remote coaching using the apps*

To assess the feasibility of providing remote coaching using the apps we measured: the number of videos shared by parents per week using KeepCam; the number of text messages from the parents within Relate; the number of messages from the therapist using Relate; and the content of the messages in Relate. Parent message content was coded to show whether messages contained information on the use/functionality of the app or were therapeutic, i.e. they related directly to parents’ or children’s communication and coaching (Table 1)

Insert Table 1 about here

Messages were downloaded and coded by a researcher blind to the therapy session content. To assess reliability in coding, a second rater coded two complete transcripts blind to the initial rater's coding.

### Analysis

We calculated the median and range of all numerical data for the feasibility analysis (e.g. number of videos recorded for analysis of parent and child behaviour for outcome measure testing; number of videos shared by parents using the app; number of messages sent by parents using the app; number of messages sent by therapist using the app; number of messages within each category for parents and therapist). Agreement between raters on the presence of child communication, child vocalisation/ production of spoken words and coding of app text message content was calculated using Kappa statistics (Cohen, 1960). Agreement on the RAACS was calculated using Spearman's rank correlation. We analysed transcribed interview data using an inductive thematic analysis as described by Braun and Clark (2006). Interview transcripts were coded and stored using NVivo 10 (2014).

## **RESULTS**

### Recruitment rate, attrition and number of therapy sessions

Nine families were recruited over 16 weeks. All children completed speech, language, cognition, gross and fine motor skills assessments to provide a comprehensive view of their abilities and support personalisation of the intervention (Table 2). All were deemed to fit the inclusion criteria for the study.

Insert Table 2 about here

Of the nine families recruited, four dropped out: one after initial assessment; two after completing initial interviews and assessment; and one at the third week of intervention. One

mother reported that she wanted to focus on intervention for gross motor skills and did not feel able to work on more than one area of development with her child simultaneously. One reported that she was unable to commit to the data collection and therapy visit schedule for the project because of work and family commitments. One reported a lack of confidence in carrying out therapy tasks at home and did not want to be the focus of a research study. The fourth reported changes to their personal circumstances, including a house move, which left little time for intervention. Because the first family to drop out of the study at a very early stage, we had sufficient time in our study timeline (which was constrained by funding arrangements) to recruit a ninth family if they were happy to receive four weeks of intervention only. Family (G) was recruited late in the project on that understanding.

Six families received intervention. Four received the planned six visits over six weeks. One family (E) received three sessions of intervention but then withdrew from the study. Family G, who was recruited late, received four visits over four weeks.

#### Completion of outcome measures

Families were asked to make three video recordings of their interaction with their child per week across the four study phases (baseline, intervention, post therapy and follow-up) for therapy outcome measures. No participant submitted a full set of video recordings (target = 39; median = 26; range 5-33). Table 3 shows the number of videos made per participant. Highest compliance with video recording occurred during the baseline and follow-up stages. The rate of video recording was lowest during the intervention phase.

Insert Table 3 about here

Almost all videos (98.2%) showed children in full view, enabling the coding of children's communicative acts and vocalisations/word productions. However, parents' communication was often difficult to measure using RAACS because the position of the video camera did not

allow full view of the mother's face and her line of view; 50.0-72.7% of videos submitted were codable using RAACS (see Table 2). Reliability of coding was moderate for communication acts ( $K=0.46$ ) and vocalisation/spoken words ( $K=0.60$ ) and almost perfect for RAACS ( $r_s$  0.96,  $p<0.001$ ).

Analysis of accelerometry data proved not possible. Parents often forgot to shake the accelerometer in front of the camera, as per the protocol, so there was no way to indicate that the data recorded was within the specified video. Devices did not always record during the programmed time-period. Furthermore, some Go Pro cameras ran out of battery power during the data-collection period and re-set to default date and time settings, making it impossible to match the accelerometry to the corresponding video time and date for reliable analysis.

Measurements from the Gross Motor Function Measure (GMFM) were undertaken for the children who completed the intervention.

### App use

Mother E reported difficulty using the app and shared five videos using KeepCam between the first and third therapy sessions, but did not annotate them with text using Relate. She then withdrew from the study. Mother A shared videos for the first three weeks of intervention. In the second three weeks she reported difficulties sharing the videos using KeepCam but did still record videos using KeepCam and showed these to the therapist during home visits.

Agreement of message coding between the two coders was high ( $K=0.74$ ). As shown in Table 4, messages from parents often commented on children's communication behaviour (e.g. 'It's the first time we've seen him do this to get someone's attention and make a request' (Mother H); 'I think [child's name] requested more when I paused (Mother F)). Therapist messages were also related to use of the app (for example, acknowledging receipt, trouble shooting) and coaching. Coaching related directly to the strategies taught. For example,

establishing joint attention: ‘These are great! When you gave her time, especially in the last video, [child’s name] vocalised then looked at you and then back at the books! I could see you using multiple types of prompt to engage her attention. Which way did you feel worked best? (Mother D). Watch, wait and listen: ‘That’s great you’ve already picked up on giving [child’s name] more time to respond to you. Giving him more time while waiting and showing you’re listening will help him understand that you’re waiting for him to do something.’ (Mother G).

Insert Table 4 about here

### Parents’ views on the acceptability of the intervention and study design

The five mothers who completed the therapy were interviewed in the two weeks after follow-up (13-14 weeks post-intervention).

#### *Intervention*

Overall, parents’ views of the one-to-one training were positive. The intervention strategies were reported to ‘make sense’ (Mother G) and were easy to follow.

It just feels like a natural progression from what we did before.

#### *Mother D*

Parents reported passing on the strategies they learned to partners, grandparents and nursery. The written advice in the communication toolbox resource (Appendix 1) was seen as a useful reminder to parents of the strategies they were working on currently and enabled them to review previous targets. Parents shared the toolbox advice sheets with others to help explain the children’s communication goals and prompts to help them achieve these goals

I’d usually send the sheet with my mum and dad for when they were looking after [child].

*Mother H*

The block format of therapy, with six visits over six weeks plus remote coaching, was seen as manageable by the parents who completed the intervention. They reported that it gave them a defined period in which to concentrate on their child's communication, to build up a rapport with the therapist and work as a team.

We see the speech and language monthly, or whatever it is, you might forget the thing that happened two weeks ago, or you might miss the little things that are important. .... we might talk about what we're doing at school or feeding, or all sorts of other issues, but with [research therapist], we could just focus on communication, and I think that was really good. ... we were a team working together.

*Mother D*

I guess with the app as well you're in constant contact and if there are any questions we can contact [therapist]. We've seen a huge difference in [child].

*Mother G*

However, the parents also proposed that fortnightly, rather than weekly, visits might be more efficient. Having two weeks between visits would allow them time to work on strategies in their busy lives with multiple competing family and work commitments. It would also give more opportunities to test if the strategies worked for them and if they needed refining or 'tweaking' (Mother G). Finally, some mothers noted that their child's rate of development required multiple practice opportunities; having greater time between appointments would allow such practice and therapy to fit with the child's developmental pace.

I would say once a fortnight. I think that's enough time in between to try the strategies, I think you would see some kind of improvements from a therapist

point of view, you'd be coming out and actually seeing some progress. I didn't mind [therapist] coming out once a week and that's not the issue. The issue being is if you're a working mum and a busy family and stuff like that. Some weeks it would be nice to tone down the appointments and stuff like that, so once a fortnight would be good.

*Mother G*

Some weeks, yes, possibly. Maybe it can be, depending on what other appointments you have. I suppose it could be quite hard going if it was every week. Yes, it would probably be better fortnightly if it was a constant thing because you do, like I say, have other appointments and stuff as well. Sometimes you're trying to squeeze (Laughter) everything in, in a week, but some weeks are quiet.

*Mother F*

*App use for remote coaching*

Parents seemed happy to communicate with the therapist via their smartphones for remote coaching and were comfortable sharing video clips and sending and receiving messages about the recordings.

I didn't find speaking to her through my phone or the app being on my phone, I didn't find that a problem at all.

*Mother A*

I liked it. It was great.... I was careful and just made sure that I was actually attaching the right video when – because I'm probably a bit like 'Am I sending

this to the right person?' I just make sure before I did that I was sending the right video

*Mother H*

Home visits were used for longer discussion and remote coaching via the app provided the opportunity for brief exchanges relating to the strategies taught. None of the parents reported issues in misinterpreting brief text messages.

Obviously face-to-face is an opportunity to elaborate and have that conversation as with anything and you can pick up on tone and things like that. Where Relate you can't do that. There were no issues in terms of what was written couldn't have been taken in a different way.

*Mother G*

However, parents had mixed views about using their phones to record interaction for therapy, showing the flip sides of using technology for more than one purpose:

I thought using the smart phone was great, because it's always charged; it's always with you.

*Mother D*

I think the idea of it was that it would just be, you know, sitting in the corner as you were going about your daily life and then oh, something's happened. It does not quite work like that because it's on your phone and you're generally just using your phone.

*Mother G*

Parents reported that they recorded both naturally occurring interactions using the app, and set up situations specifically to generate recordings for therapy. However, capturing naturalistic interaction with the app was sometimes problematic as the smartphone required ‘setting up’ on the tripod to film both the child and the parent.

If I could have had a camera in the corner and a little trigger, might have been easier than my phone, because I use it, and I had to keep taking it down.

*Mother H*

All parents reported that making the video recordings for remote coaching had helped them to focus on their child’s communication and to identify communication behaviours more easily, and that having the video helped reduce misunderstandings that might appear in descriptions of behaviour.

I would think ‘Wow!, [Child] really did ask there.

*Mother E*

All had shared videos with partners or other family members, and some had also used the recordings to their child’s progress. Mothers reported that they recorded –three to ten videos and shared two to three per week for remote coaching. This level of exchange was seen as feasible, but they felt that any greater frequency might burden the therapist: “*you don’t like to hassle people*” (Mother E).

Technical issues with the apps’ functionality in the first three weeks had an impact on video sharing.

Because it was not sending back and forward it just became a task, because I was having to delete it and upload it again and it just was like, “Oh I give up I’m going to throw it out the window”.

*Mother A*

While these issues are to be expected in a testing stage, there may have been an effect on app use, as all participants reported time pressures as being their main barrier to submitting videos,

We've got busy weeks so if it doesn't work first time I don't have time to do it again and again.

*Mother D*

*Recording interaction for outcome measurement*

Parents reported that videoing interaction for 10 minutes 3 times a week was achievable initially, but as the study went on some found it too invasive and hard to fit in to family routine, particularly when there were other siblings or family members present.

It felt a little bit like an intrusion of privacy, do you know what I mean? ... I found it quite hard to capture a time that was ideal.

*Mother A*

The busy nature of family life and unexpected events, such as siblings joining the play, family holidays, and work commitments led to parents abandoning recordings or not being able to complete the target three recordings per week. One mother (D) also felt that she had not managed to capture the best communication from their child on the videos, and in other interactions the child had vocalised more frequently than in the recordings.

**DISCUSSION**

Results of the study suggest that it is possible to provide remote communication coaching via an app system to parents of young children with neurodisability. However, the high attrition rates we encountered suggest that the intervention and/or research design to measure its effectiveness was not acceptable to all families.

#### Intervention feasibility and implications for intervention future study design

Five out of six parents who started the intervention received all planned home visits in which the therapist introduced and modelled communication strategies that have been shown to be effective in other research: watch, wait, listen; face to face; taking turns and adding language to interaction (Girolametto, 1988, Girolametto et al., 1998, Mahoney et al., 1998, Roberts and Kaiser, 2011, Roberts and Kaiser, 2012). Interviews with parents suggested that the therapy content and method of delivery was acceptable to those who completed it. Parents passed on the written advice to family and nursery staff, which may promote generalisation of communication techniques. Most parents who completed the intervention sent multiple videos and text messages to the therapist per week, commenting on their child's communication shown in the videos, and received coaching messages on strategy use by return. Two families reported difficulties with the app and although these were resolved for one family, they may have contributed to the second family withdrawing from the study. Further refinement of the apps may be required: future use could include troubleshooting information such as written and pictorial support provided as part of the system or in a separate booklet.

For the families who resolved their difficulties with app function, the apps appeared to fit with parents' typical use of their smartphone, which should aid adoption (Murray et al., 2010). However, one parent commented that using the app to make videos for coaching precluded regular use of her phone. A longer period of intervention may have enabled that

parent to find ways to combine app use with regular phone use and for app use to become routine: further testing of continued app use over time is required. Longer intervention periods were also supported by parents, who reported that although the intensive six weeks of visits and remote coaching enabled them to focus on communication for a defined period, fortnightly therapy would be easier to manage. Having longer gaps between visits would give parents greater opportunities to practise therapy techniques with their child and for secondary effects on children's communication to occur. Other training programmes that teach parents similar communication strategies have been delivered over longer periods, which may allow new practices to become embedded (Girolametto, 1988, Girolametto et al., 1998, Mahoney et al., 1998, Yoder and Warren, 2002, Warren et al., 2008, Pennington et al., 2009, Ronski et al., 2010, Roberts and Kaiser, 2012). Further research is needed to determine the most efficient manner of delivering training to families and the optimal timing of sessions (Warren et al., 2007).

It is interesting to note that although the intervention focusses on parent behaviour and adapting parent communication to promote children's interaction, few parents commented on their own behaviour captured on the videos or their use of the strategies. This may be because parents focus on child outcomes, but also perhaps because they feel more comfortable talking about their child's behaviour rather than their own. A longer intervention period may have shown a change in patterns of parental reflections, as they became more comfortable using the app, but all reported feeling at ease communicating via the system. Future research should test the parents' awareness of their mastery of the techniques introduced, as well as their awareness of change in their children's behaviour, for generalisation and maintenance of skills (Hargreaves and Dawe, 1990, Dunst and Trivette, 2009). This could partially be achieved through analysis of the parents' text messages in Relate.

Although overall, parents who completed the intervention were positive about its content and the use of remote coaching via the apps, it must be acknowledged that the intervention did not suit all families. Four parents withdrew from the study, three before intervention had started and one halfway through the therapy period. The parent who withdrew during the intervention reported that she wanted to focus on gross motor skills and mobility, and did not feel able to work on more than one area of development concurrently. Our previous research has shown that parents may prioritise developmental areas at different points during their child's lives and that parent communication training may be offered several times before the time is right for parents (Pennington and Noble, 2010). It is possible that the parents who withdrew from the current study were not currently prioritising communication and therefore intensive communication intervention was not appealing at that time. However, to gain better understanding of families' reasons for withdrawal we may need a trusted third party with whom parents could share views about interventions offered. In our previous research, parents have reported that physiotherapists provide the most consistent level of continuing care and often become trusted advisers (Pennington and Noble, 2010), and we have used these professionals to help us recruit participants (Pennington and Pearce, 2012).

Nevertheless, although recruitment via healthcare professionals may offer parents an opportunity to be open about why they opting out, it also opens the risk of gate-keeping and consequent under-recruitment (Sharkey et al., 2010, Tromp and Vathorst, 2015). Future researchers should design methods of recruitment with parent and multi-disciplinary team representatives that can provide balanced information about research to all families who fit the criteria from trustworthy sources and capture reasons for opting-out (Treweek et al., 2013, Greenberg et al., 2018). Measures of parent characteristics, such as familiarity with technology, education and employment, may also help to identify the families for which the intervention is most suitable.

### Research feasibility and implications for future study design

Slow recruitment rate and loss of participants may also be attributable to our research design. The current study aimed to assess the suitability of SCED in further trials and required parents to video record interaction with their children three times per week across the study (in addition to sharing videos for remote coaching using the app), so that the rate and direction of communication change could be evaluated (Kratochwill et al., 2010). As in previous research (Pennington et al., 2009), recording periods were set at 10 minutes to show interaction patterns within and across play activities. Such intensive measurement may not be feasible for parents of young children who already have multiple demands of work and family life and the additional demands of raising children with neurodisability who can face multiple appointments per week (Pennington and Noble, 2010) if substantial changes to usual behaviour are required. Parental reports of difficulties of setting up the video cameras and feelings of intrusion and the fact that none of the parents who participated in all stages of the study managed to submit the target number of video recordings for outcome measurement, all support the conclusion that using additional technology to make frequent recordings at home over several months is not currently feasible. We had originally planned that parents would record interactions for outcome measurement using their smart phones, which may have reduced disruption as parents were already recording children in this way. However, limitations in storage capacity prevented this. Future technological advances could enable parents to make longer recordings for outcome measurement using their phones. Wearable technology that counts vocalisation throughout the day could also be used to measure the frequency of children's vocalisations (Boggiano et al., 2018), although this technology may not be suitable for measuring parents' communicative behaviours. One final point about the equipment used in the current study is that accelerometry, as a control measure of children's

body movements, was not successful due to difficulties in compliance with the protocol and equipment failure. If control measures are required in future studies, validated measures such as the GMFM, which were completed successfully here, could be used.

We measured communication change through coding video-recorded child and parent behaviours. As discussed, parents were unable to complete frequent recordings, which prevented observation of patterns of communication change over time. Agreement on coding parents' behaviours using RAACS was high. The measure is quick and easy to use and our results support its retention in future trials. However, future research should include training on how to produce videos for analysis. Within the videos it was often not possible to code parents' behaviours because they were (partially) out of shot. Whereas agreement on subjective rating of parents' communication behaviours was high, we achieved only moderate agreement between coders on children's communication behaviours. This may be due to difficulties in determining children's line of visual regard or unfamiliarity with the individual children recorded when determining if communication was intentional (Coggins and Carpenter, 1981). In future studies, familiarisation with individual children and notes on their idiosyncratic communicative behaviours may help to increase coding agreement (McConachie et al., 2005). Validated measures of communication development, such as the Communication and Symbolic Behaviour Scale Developmental Profile (Wetherby and Prizant, 2002) which we used as a descriptor measure to ensure children fitted our inclusion criteria, have been shown to capture change over time for children with motor disorders (Coleman et al., 2013, Coleman et al., 2015) and may serve as secondary outcome measures to capture generalised communication change.

### Implications for practice

Many therapists are currently providing training for parents, either to groups or individual families (Watson and Pennington, 2015). Further development of the apps used here, refinement of the therapy protocol and testing in controlled trials is required before recommendations can be made about their use in clinical practice. However, the high agreement achieved in the scoring of the RAACS, may suggest that this measure could be implemented to evaluate currently provided parent training.

### Limitations

This preliminary study has several limitations. Feasibility was tested with a small number of families. Half of the families withdrew from the study, which is not unusual in technology studies (Hall and Bierman, 2015). But, withdrawal attrition before interview meant that we were unable to ascertain which features of the research design and/or intervention that did not meet parents' expectations or fit with their family life. We took very few measures of parents' characteristics, which could have pointed towards factors that could influence parents' views of the study design, intervention and adoption of the apps. Fidelity of implementation of the intervention was not explicitly measured during this study, as the focus was on the acceptability and feasibility of using the app system.

### Conclusion

This initial study shows that for some families, one-to-one parent training in interaction that incorporates evidence-based techniques from group training and coaching via smartphone apps may be feasible. Further evaluation of the effectiveness of the intervention is warranted, as the intervention uses ubiquitous technology that could allow remote coaching and potentially reduce therapy costs, and research design features could be changed to improve acceptability. A pilot randomised trial with pre and post intervention measurement only and a

concurrent process evaluation to assess intervention delivery could determine whether a full randomised controlled trial is justified (Craig et al., 2008).

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**Table 1 Categories coding app message content**

<b>Sender</b>	<b>Category</b>	<b>Definition / example</b>
Parent	App use	Reporting technical issues or describing app use/ video content e.g. “I couldn’t send my video last night”
	Request for support with strategy use	‘I can’t stop myself jumping in. How do I make myself wait?’
	Comment on child’s behaviour	‘He was really watching me then’
	Comment on strategy	‘Waiting longer gave her a chance to look at me and vocalise’
	Comment on own behaviour	‘I gave her the wrong book. She looked at the other one’
Therapist	Technical issue / app use	Trouble shooting. E.g. “The video you sent came through this morning”
	Comment on child behaviour	“He watched you closely when you opened the box”
	Comment on parent behaviour/strategy use	“Well done you watched and waited for him to tell you to open it”
	Advice	Therapist gives parent advice without reflection on current behaviours. E.g. “Keep repeating the word in

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different ways, so she hears it in lots of different ways”

Coaching

Comment on child or parent behaviour AND request for reflection or action. E.g. “You watched and waited for a little while there. Did it feel like you could wait just a little longer? He looked really interested.”

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**Table 2: Participant family characteristics**

	<b>Family</b>							
	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<b>E</b>	<b>F</b>	<b>G</b>	<b>H</b>
<b>Family composition</b>	Mother, partner, 2 older siblings	Mother, Father	Mother	Mother, Father, 2 older siblings	Mother	Mother, Father, 3 older siblings	Mother, Father	Mother, Father
<b>Parent Employment</b>	Mo: no paid employment Fa: employed full time	Mo: employed part time Fa: part time	Mo: no paid employment	Mo: employed part time Fa: full time	Mo: no paid employment	Mo: no paid employment Fa: employed full time	Mo: employed part time Fa: employed full time	Mo: employed part time Fa: employed full time
<b>Deprivation rank*</b>	9	4	1	5	4	4	10	10
<b>Child Sex</b>	M	M	F	F	M	F	M	M

<b>Child age at assessment (months)</b>	35	39	24	27	13	19	31	28
<b>Diagnosis</b>	CP spastic unilateral	CP spastic bilateral	CP spastic unilateral	CP spastic bilateral	CP spastic bilateral	CP spastic bilateral	CP bilateral	Global delay and hypotonia
<b>Age at diagnosis(months)</b>	18	37	18	12	12	12	6	6
<b>GMFCS:<sup>1</sup></b>	II	IV	III	V	V	V	II	II
<b>MACS:<sup>2</sup></b>	II	IV	III	IV	IV	V	II	II
<b>PLS-4:<sup>3</sup> Receptive language(%ile)</b>	1	1	7	1	1	1	1	1
<b>PLS-4:<sup>3</sup> Expressive language(%ile)</b>	1	1	9	1	1	3	1	1

<b>Mullen<sup>4</sup>: visual perception: (AE months)</b>	14	14	17	12	6	9	Not completed due to late recruitment	9
<b>CSBS<sup>5</sup> (%ile)</b>	21	32	23	1	1	26	1	1
<b>GMFM<sup>6</sup> score pre-therapy</b>	27/88	Not measured	Not measured	15/88	Not measured	9/88	Not measured	28/88
<b>GMFM<sup>6</sup> score post-therapy</b>	Insufficient data	Not measured	Not measured	9/88		9/88	Not measured	33/88

\* Calculated using postcode with 1 being most deprived and 10 being least (in comparison with other small geographical areas, 1= one of 10% most deprived areas in the country) (*English Indices of Deprivation, 2015*)

1) **Gross Motor Function Classification System** (Palisano et al., 1997), 2) **Manual Ability Classification System** (Eliasson et al., 2006), 3) **Pre-School Language Scales-4** (Zimmerman, Steiner, & Pond, 2002), 4) **Mullen Scales of Early Learning Assessment: (Mullen, 1993)**, 5) **Communication and Symbolic Behaviour Scales (Wetherby & Prizant, 1993)**, 6) **Gross Motor Function Measure** (Dianne J. Russell, Peter L. Rosenbaum, Marilyn Wright, 2013)

**Table 3: Number of video recordings submitted by families for each phase for therapy outcome measurement (target number of videos) and number of therapy sessions**

<b>Family</b>	<b>Baseline (9)</b>	<b>Intervention (18)</b>	<b>Post- intervention (9)</b>	<b>Follow-up (3)</b>	<b>Possible to code for child communicative behaviours (%)</b>	<b>Possible to code for parental behaviours using RAACS (%)</b>	<b>Number of therapy sessions received</b>
<b>A</b>	2	3	0	0	3 (60.0)	3 (60.0)	6
<b>D</b>	9	6	8	3	26 (100)	15 (57.7)	6
<b>E</b>	2	1			3(100)	2 (66.7)	2
<b>F</b>	9	10	8	3	30 (100)	18 (60.0)	6
<b>G</b>	3*	7*	3	3	16 (100)	8 (50.0)	4
<b>H</b>	9	15	6	3	33 (100)	24 (72.7)	6

\*Family G received two weeks of baseline and four weeks of therapy; target number of videos during the intervention phases = 12



**Table 4. Number of app messages shared using Relate by parents and therapists coded according to their content**

App message category	Family					
	A	D	E	F	G	H
<b>Parent</b>						
App use	9	12	4	7	37	14
Comment on child behaviour	3	20	0	11	4	15
Comment on own behaviour	0	0	0	0	0	0
Use of strategy	1	2	0	0	3	3
Acknowledgment of therapist's message	2	0	0	0	1	0
<b>Therapist</b>						
App use	10	4	2	2	9	1
Comment on child behaviour	2	1	0	0	0	0
Comment on parent behaviour/ strategy use	8	0	0	0	2	0
Advice	3	1	0	0	0	0
Coaching	8	11	1	8	8	6

**What is already known on this subject.**

Children with motor disorders have difficulty developing independent communication. Training is often provided to parents to help them promote their child's communication development. Training is often delivered to groups of parents and involves video coaching to help parents apply techniques learned in the group. Training has been associated with increases in parents' responsiveness in interaction with their children and with increases in the range of communicative functions expressed by children, their frequency of communication and their vocabulary.

**What this study adds.**

It may be feasible to deliver training to parents individually and to support this training with remote coaching using smartphone apps. However, we had a 50% attrition rate in this preliminary study. Loss of families from the research suggests that frequent contact with families of preschool children with neurodisability via smartphones and/or home visits may not be feasible and research designs that necessitate frequent recording of interaction using separate cameras, may not be appropriate.

**Clinical implications of this study.**

Therapists could explore using smart phone video recordings of parent-child interaction taken in daily interactions for parent child interaction coaching with their clients. Parents could record interaction at their convenience and review this with their clinician in therapy sessions.

## Appendix

### Communication toolbox: Weekly strategy sheet 1

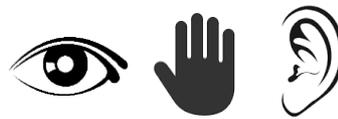


#### Session 1

This week's tools are.....

Getting face to face

Watch, wait, listen



Try to wait for a bit longer than is comfortable after you've had your turn. It can help to count to 5 or 10 in your head. This gives time to respond to your communication request.

Watch and listen to what [ ] does

Try it again, did something different happen? Don't forget to send me videos of you using the strategies