

Following children with severe or profound intellectual and multiple disabilities and their mothers through a communication intervention: single-case mixed-methods findings

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There is limited research targeting communication interventions for children with severe/profound intellectual and multiple disabilities. This study addressed outcomes from a communication course for parents of children with severe/profound intellectual and multiple disabilities and follows up on a previous publication by Rensfeldt Flink *et al.* (2020). Potential observable changes in the children's and parents' communicative behavior were studied as well as the parents' experiences of the intervention process and the effect of the course on parent–child communication. A mixed-methods design with a case-study framework was used. Two mother–child dyads participated. Data were collected before, during, and after the course. Video-recorded repeated play interactions by the dyads were coded and analyzed for the mothers' responsiveness and use of augmentative and alternative communication and the children's interactive engagement. Longitudinal interview data from the mothers were analyzed thematically. No clear signs of behavioral change were observed in the coded video data. However, thematic analyses showed that the mothers experienced changes to communicative behaviors. Moreover, the course affected both mothers' reasoning about communication with their child and their child's communicative needs. The mothers' narratives contributed insights into how reflective processes might guide action in parent-mediated communication interventions. The implications for research and clinical practice are discussed.

Keywords: severe disabilities; profound intellectual and multiple disabilities; communication intervention; parent-mediated intervention; AAC; parental responsiveness

Introduction

AKKtiv ComAlong is a manualized and group-administered parental communication course. (AKKtiv is a Swedish acronym translating to 'AAC Early Intervention'). It is designed to suit children with a variety of communication disabilities (Ferm *et al.* 2011, Jonsson *et al.* 2011, Rensfeldt Flink *et al.* 2020, Fäldt

et al. 2020) and is widely used in clinical settings in Sweden (Kjellberg 2019) and also a number of other countries. This study aims to explore possible intervention outcomes when AKKtiv ComAlong is implemented with parents of children with profound intellectual and multiple disabilities (PIMD).

Children with PIMD have severe motor disabilities combined with such severe cognitive disabilities that standardized tests assessing IQ are hard to administer (Nakken and Vlaskamp 2007). Sensory disorders (particularly visual impairment) and medical conditions such as epilepsy are commonly found (van Timmeren *et al.* 2016). Because of this combination of multiple

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disabilities and medical conditions, children with PIMD rely on support from others in almost all daily activities and in managing communication (Nakken and Vlaskamp 2007). Children with PIMD communicate preverbally at the level of either preintentional or intentional behavior (Dhondt *et al.* 2020).

Parental responsivity (i.e. the parent being sensitive to and responding contingently to the child's cues, following the child's lead, and basing his/her own communicative initiatives on the child's focus of attention) is argued to promote development in children with disabilities (Spiker *et al.* 2002). Responsive and sensitive communicative behaviors in the communication partner are also agreed to be important in communication with individuals (children as well as adults) with PIMD (Neerinckx and Maes 2016, Hostyn and Maes 2009, Van Keer *et al.* 2017). It has been argued that certain communicative behaviors (or the lack thereof) in children with disabilities may disrupt parents' use of a responsive communication style (Warren and Brady 2007), possibly meaning that parents of children with PIMD may exhibit a less responsive communication style. However, in a recent study addressing children with significant cognitive and motor delay and their parents, parents generally scored high on measurements targeting a responsive communication style (Van Keer *et al.* 2017); similar results were also found in a study addressing parents of children with significant motor disorders (and varied cognitive abilities) (DeVeney *et al.* 2016). In a qualitative study, parents of children with PIMD characterized their role as 'sensitive leaders' when communicating with their children (Wilder and Granlund 2003), which suggests a responsive style. In the study by Van Keer *et al.* (2017) the children's level of attention and initiation while communicating was shown to correlate positively with their parents' use of a responsive communication style, although no causal conclusions could be drawn in their cross-sectional study. Still, based on current knowledge it has been recommended that communication interventions for children with PIMD should include training for parents in the use of responsive strategies (Van Keer *et al.* 2017, Bruce and Bashinski 2017) and research targeting such interventions is warranted.

Augmentative and alternative communication (AAC), both unaided (building on vocal behaviors, gestures, and signs) and aided (e.g. using objects of reference or various kinds of assistive technology), is assumed to represent an appropriate resource for individuals with severe or profound intellectual disabilities and the involvement of communication partners in the intervention is considered crucial (Ogletree and Pierce 2010, Bruce and Bashinski 2017). According to a British survey of speech-language pathologists (SLPs), AAC was used clinically for children with PIMD and object-based AAC was the most used approach

(Goldbart *et al.* 2014). In a Swedish survey of SLPs' practices in relation to individuals with Rett's syndrome (who sometimes but not always have PIMD), aided AAC was commonly included in communication intervention (Wandin *et al.* 2015). However, there are knowledge gaps when it comes to AAC practices in relation to children with PIMD. In a recent review of aided AAC in the PIMD population, it was found that although AAC was successfully implemented across a variety of participants, very few studies involved preschool children (or their parents). Moreover, in the existing studies, treatment intensity was often underreported and intervention goals beyond AAC-supported requests (e.g. child using a speech output device to request attention or a preferred object) were uncommon (Simacek *et al.* 2018).

Active involvement of significant communication partners in communication interventions is important for all individuals with severe disabilities, but for children with PIMD in particular (Bruce and Bashinski 2017). The term 'parent-mediated communication intervention' can be used to characterize interventions aimed at teaching specific intervention strategies to parents, who will then incorporate those strategies into their everyday interactions with their child to enhance his or her communication development (Lieberman-Betz 2015). In a recent scoping review, it was suggested that parents are able to learn and successfully implement naturalistic communication strategies in relation to children with a variety of disabilities and developmental delays (Akamoglu and Meadan 2018). Moreover, positive outcomes were reported for the children in the studies included. These results are in line with those of a previous systematic review (Rakap and Rakap 2014).

There is limited intervention-oriented research targeting parental strategies for stimulating communicative behaviors in children with PIMD (Van Keer *et al.* 2019, Wilder and Granlund 2003, Bruce and Bashinski 2017). In one home-based parent-mediated communication intervention addressing parents of children with PIMD including a visual impairment, the parents experienced that they changed their communicative behavior with their children (Chen *et al.* 2007). Also, the AKKtiv ComAlong Course has been scientifically explored with regard to how it is experienced by parents of children with specified PIMD (Rensfeldt Flink *et al.* 2020). The course is a parent-mediated communication intervention and aims to teach parents how to identify the communicative level and behavior of their child, how to appropriately use naturalistic communication strategies (responsive strategies and milieu-teaching strategies), and how to implement AAC in everyday communication in the home (Ferm *et al.* 2011, Rensfeldt Flink *et al.* 2020). AKKtiv ComAlong consists of theme-based sessions. In between each session there are home assignments (such as applying



Figure 1. Procedural diagram illustrating the study’s case-by-case data collection, analyses and integration of results from both statistical and thematic analyses.

responsive communication strategies or using AAC boards with the child), and the course is taught by accredited course leaders (Rensfeldt Flink *et al.* 2020, Ferm *et al.* 2011). In a recent study, it was found that when the AKKtiv ComAlong course was offered to parents of children with PIMD in PIMD-specific groups (referred to below as ‘PIMD-specific AKKtiv ComAlong’), the parents gave the intervention very high ratings and appreciated the social learning environment provided by course leaders and other participants (Rensfeldt Flink *et al.* 2020). The thematic analysis included themes related to increased adaptation of parents’ communication to their children as a result of what they had learned on the course. Such changes to communication most commonly involved parents giving their children more time to initiate or respond as well as parents applying AAC more or in new ways compared with before the course. However, it was not clear whether the parents considered that their adjusted behavior had caused any changes in their children’s communication. Further, the results were inconclusive when it came to the parents’ attitudes toward AAC after the course: most took a positive view of using AAC with their child after the course, but a significant minority of parents were hesitant about the AAC-related part of the course (Rensfeldt Flink *et al.* 2020). Such parental hesitancy about AAC use in relation to children with severe disabilities has also been reported previously (Stephenson and Dowrick 2005). While the PIMD-specific AKKtiv ComAlong course seems to have affected many parents’ understanding of communication with their child, the qualitative data of the study were restricted to shorter, written statements without the possibility for follow up-questions (Rensfeldt Flink *et al.* 2020) and it has not yet been explored what the links are between the parents’ own perceptions of changes to their knowledge and behavior, on the one hand, and observable changes to the parents’ behavior and to that of their children with severe disabilities, on the other.

It is unarguably a complex task to carry out research into parent-mediated communication interventions, because such interventions target both parents and children, aiming to affect both in a stepwise process. This intervention complexity can hardly be fully captured by research questions along the lines of ‘Does it work?’, because they are not sufficiently sensitive to identify the mechanisms underpinning the chain of events. In

the present study, we sought not only to explore potential changes in the parent’s and child’s communication following the AKKtiv ComAlong course, but also to disentangle the mechanisms of possible change as seen from the parent’s perspective and to explore how *observed* communication behaviors may relate to *experienced* communication behaviors. To this end, we closely observed, coded, and quantified various aspects of communication behaviors manifested by the parent and child as well as analyzed the mothers’ descriptions about their experiences of the intervention process.

The study aimed to answer the following research questions: (1) Do exhibited communication patterns during parent–child play change when it comes to (i) the parents’ responsivity and/or AAC use and (ii) the children’s interactive engagement during and after the course attended by the parents?

(2) What are the parents’ experiences of the intervention process and how do those experiences relate to exhibited behaviors and to possible behavioral changes in the communication between the parents and the children?

Methods

Study design

The study applied a convergent mixed-methods design with a case-study framework (Fetters *et al.* 2013). Mixed-methods research integrates quantitative and qualitative data to make interpretations drawing upon their combined strengths. In line with the convergent mixed-methods design, separate analyses of both kinds of data were performed before the quantitative and qualitative results were integrated (Creswell 2015).

The case-study framework consisted of multiple repeated measures in three phases (an AB design (Byiers *et al.* 2012) with an added follow up phase): (1) baseline; (2) an eight-week intervention; and (3) follow-up immediately after the intervention phase as well as (qualitative) follow-up one year later. See Figure 1 for illustration of the study design.

Data were collected from two parent–child cases. Each case was analyzed separately. The quantitative data consisted of coded social attention and communicative behaviors in the child and responsive communicative behaviors by the parent as well as use of AAC by the parent (video-recorded 10-minute parent–child play sessions in the respective home). Dependent

Table 1. Overview of the duration and timing of the video-recorded data.

	<i>Dyad 1: Hanna and Jenny</i>		<i>Dyad 2: Sam and Sara</i>	
	Number of filmed sessions (min)	Mean number of days between sessions	Number of filmed sessions (min)	Mean number of days between sessions
Baseline	5 (50)	16,5	4 (36)	19,3
Intervention	3 (30)	18,0	2 (20)	13,0
Follow-up	3 (30)	13,5	3 (30)	26,0
Total	11 (110)		9 (86)	

Note. The phases (baseline, intervention and follow-up) were carried out back-to-back.

variables for the parents (responsivity and AAC use) were chosen since these are behaviors that are taught in the ComAlong course. Dependent variables for the children (communicative attention and initiation) were chosen because of prior findings indicating positive correlation between parent responsivity and child initiation and attention in children with PIMD and both are key aspects of communicative functioning in children with PIMD (Van Keer *et al.* 2017). The qualitative data were derived from semi-structured interviews with the parents. While qualitative, longitudinal case studies are rare, we were inspired by a few similar papers previously published in the fields of health-care science (Le Dorze *et al.* 2009) and educational science (Scott 2013). The qualitative and quantitative results are integrated in the Discussion section.

Participants

The participants were recruited through the public habilitation services for children and adolescents in Region Västra Götaland, one of Sweden’s larger regions. Those services provide multidisciplinary, goal-oriented interventions free of charge to all children in Sweden with intellectual disabilities (and their parents) (Wettergren *et al.* 2016). The inclusion criteria were the following: (i) The parents had to be on the waiting list to attend the AKKtiv ComAlong parental-communication course targeting parents of children with PIMD; (ii) the children had to be diagnosed with a severe or profound intellectual disability (World Health Organization 2016); and (iii) the children had to have motor disabilities corresponding to level IV or V on the Gross Motor Function Classification Scale (GMFCS) (i.e. the children had to have no or very limited independent mobility) (Palisano *et al.* 1997). Over a period of two years, two members of the staff at the clinic approached a total of thirteen families on the waiting list for the course by letter and telephone three or four months before their course was due to start. Two parents agreed to participate in the study with their children. Both parents and children are referred to with fictitious names in the following.

‘Hanna’ was 7:7 years old at the beginning of the study. She had profound intellectual disability as well as a cerebral palsy that severely limited her motor abilities. Hanna was dependent on a wheelchair to ambulate

in most instances but could occasionally roll or crawl to move more independently while playing on the floor. She attended a special school for children with severe disabilities and had personal assistance in the home to cope with daily activities. Hanna’s mother, ‘Jenny,’ attended the AKKtiv ComAlong course. Hanna had been subject to other communication interventions previously, and her parents had some knowledge of the AKKtiv ComAlong course and the course material beforehand. Jenny was fluent in Swedish, which was the only language spoken in the family.

‘Sam’ was 2:9 years at the beginning of the study. He had a cerebral palsy that severely limited his motor abilities. He could not sit independently, and he used a wheelchair for ambulating. He had been diagnosed with a severe intellectual disability and had a confirmed visual impairment, even though it was still not known whether he had some functional eyesight. Sam attended a regular preschool (day nursery) on a part-time basis. Sam’s mother, ‘Sara,’ attended the AKKtiv ComAlong course, which was the first communication intervention in which the family had participated. The family spoke a language other than Swedish at home and Sara used an interpreter during the course. For family reasons, Sara was unable to attend the last three sessions of the course.

Procedure

Video recordings of parent–child play

Video recordings of each mother and her child playing were performed in the respective family home. The mothers were instructed to choose frequent play activities that both they and their child would enjoy. Hanna and Jenny played in the living room of their home, sitting/lying on a play mat placed on the floor. Sam and Sara played in Sam’s room, either sitting/lying on the floor, moving around in the room, or sitting/lying on Sam’s bed. Sara spoke both Swedish and her native language during play. With both dyads, a sibling was sometimes present in the room and occasionally interacted with the mother or the child. The video recordings were performed using two video cameras mounted on tripods that recorded from different angles. The first author performed the recording and generally stayed in the room while filming took place, to control the angle of one of the cameras. However, Hanna was

Table 2. Topics addressed in the interview guide and examples of questions asked.

Topic	Sample questions
The child's communication and communicative development The communication partner's optimal communication style and adaptations to the child	<i>What is special or personal about how your child communicates? If you were to instruct someone else in how to communicate with your child and how to adapt their communication to suit your child, what would you say? Do you use any particular strategies to attract and keep the attention of your child? Have you changed as a communication partner since the last interview? How?</i>
Previous and ongoing communication interventions	<i>Has your child received any communication interventions before? Which ones? Does he/she use any communication aids?</i>
Expectations of/experiences from the AKKtiv ComAlong course	<i>What are your expectations of the AKKtiv ComAlong course? Is your child benefiting/has your child benefited from your participation in the course?</i>
Expectations of the child's communicative development	<i>How do you see your child communicating five years from now?</i>

occasionally distracted by the first author's presence, and when this happened the first author temporarily left the room. Filming stopped when 1 min of video material had been recorded. On one occasion, Sara stopped the filming earlier because she felt uncomfortable. An overview of the film data included in the study is shown in Table 1.

Interviews with the parents

The first author performed semi-structured interviews with the mothers in their respective homes. An interview guide was used; it addressed the topics shown in Table 2. The topics of the interview guide were covered without any particular order, to ensure a relaxed conversation and follow-up questions were asked as appropriate (Kvale 2007). The interviews were audio recorded and transcribed verbatim by the first author.

Jenny was interviewed before the course started, immediately after the last session, and a year later. Her interviews lasted for a total of 201 min. Parts of the second and third interviews (approximately 15 min in all) were excluded from the transcript because Jenny talked about an ethically sensitive topic that was irrelevant to the research questions. Sara was interviewed twice (total interview time: 136 min). She declined to participate in the one-year follow-up interview because of a shortage of time.

Intervention

During the intervention phase of the study, Jenny and Sara attended a PIMD-specific AKKtiv ComAlong course at one of the local habilitation centers for children, in line with standard clinical practice. The themes of the eight course sessions were in line with the original course curriculum. In chronological order, they were as follows: (1) *Communication* (an overview of interpersonal communication and a short introduction to AAC); (2) *Communicative development* (a comprehensive model of communicative development from unintentional actions to combining symbols); (3) *Being your child's communication partner* (responsive communication strategies and environmental-milieu teaching

strategies); (4) *Play* (play as an important part of children's communication, development, and learning); (5) *AAC* (overview of AAC methods and tools); (6) *AAC in everyday life* (aided language stimulation and how to choose AAC symbols and vocabulary); (7) *AAC workshop* (creating personalized AAC with support from course leaders); and (8) *Communicative rights* (access to communication as part of human rights) (Rensfeldt Flink et al. 2020).

The course leaders (an SLP and a special educator) were consulted by the first author and asked whether any particular adaptations had been made to the AKKtiv ComAlong curriculum to suit the specifically addressed PIMD population. The course leaders reported that their main adaptations involved (i) using only illustrative videos from the course material that showed children with moderate-to-severe disabilities; (ii) placing less emphasis on the developmental stages beyond single-word use; (iii) demonstrating and distributing AAC boards with a limited vocabulary; and (iv) giving individually tailored examples and assignments to the parents of the children with the most severe disabilities.

Data coding and analysis

Coding of parent responsivity and AAC use

The filmed play sessions were coded with respect to each parent's responsivity and use of AAC, using the Responsive Augmentative and Alternative Communication Style (RAACS) scale, version 4 (Lindberger 2020). The RAACS scale is an instrument designed to assess and quantify responsivity and AAC use in communication partners communicating with children who have disabilities. Version 3 of the scale has been reported to show acceptable-to-perfect interrater reliability (Stockwell et al. 2019, Broberg et al. 2012) and excellent internal consistency (Broberg et al. 2012) when applied to interaction with children having various disabilities (generally milder than PIMD, though). Version 4 of the RAACS scale represents a slight adjustment, and the instructions have been accommodated to suit assessment of interactions involving pre-symbolic children, which resulted in increased interrater

reliability (Lindberger 2020). RAACS 4 consists of seven items that are coded minute-by-minute and address specified behaviors such as *'the parent gives the child space to communicate'*, *'the parent communicates according to the child's focus of interest'* or *'the parent uses AAC'* (Lindberger 2020). Another three global items (*'the parent is engaged in the child'*; *'the parent adapts to the child'*; *'the parent adjusts to the communicative level of the child'*) broadly assess the interaction as a whole (Lindberger 2020). The mean scores for the minute-by-minute items (scale: 0–2) and the total scores for the global items (scale: 1–3) are added up to form an overall RAACS score. The maximum value is 23 and a higher score indicates that the parent's behavior is more responsive (Lindberger 2020).

RAACS coding was performed by two SLP master's-level students under the supervision of the first and the senior (fifth) author. The coders first trained on filmed material unrelated to the present study. In a first stage, they carried out consensus coding to calibrate themselves to the scale. Then they coded training material independently until they exceeded 80% exact agreement. During coding of the study data, the coders were blind to the chronological order of the videos. To enable assessment of interrater agreement, 30% of the data from each dyad was randomly chosen to be scored by both coders. To begin with, their proportion of exact agreement was deemed inadequate, and especially so for scores of Jenny's communicative behavior. For this reason, one extra video from Hanna and Jenny's material was added to be scored by both raters. The data that initially generated too low agreement were discussed and (individually) rescored until acceptable agreement was reached. Following this repeated calibration, the final level of interrater agreement for scored videos varied between 77% and 90%, with a mean of 83%, which was deemed acceptable. Subsequently, the remaining video material was divided between coders and individually scored.

Coding of child interactive engagement

Each child's interactive engagement was coded using the Child Behavior Rating Scale (CBRS) (Mahoney 1998). The CBRS (Mahoney 1998) consists of a total of seven items. There are four items that address different aspects of the child's attention behaviors (*attention to activity*, *persistence*, *involvement* and *compliance*) and three items that address the child's initiation behaviors (*initiating activities*, *initiating the adult* and *affect*). Each item is scored with two-minute intervals on a five-step scale where a higher score indicates a more advanced attention or initiation behavior. The CBRS has been used in prior research on children with PIMD and their parents, and the reliability scores reported were good (Van Keer et al. 2017).

CBRS coding was performed by the third author and the senior author, who have both relevant knowledge

and practical experience. Before coding the study data, they trained on films not part of the study data together with the first author. They first engaged in consensus coding and then moved on to individual coding, which continued until the level of exact agreement exceeded 50% and no conflicting scores were more than one step apart on the five-step scale. This was followed by a thorough consensus discussion about conflicting scores. During coding of study data, the coders were blind to the chronological order of the videos. The coders first performed independent coding on 20 min of data, but they did not reach satisfactory agreement (defined as >50% exact agreement and >90% mutual agreement within one point, in accordance with a previous study (Van Keer et al. 2017)). Conflicting scores were then once again discussed for consensus. After this, another 20 min of data were coded independently. This time the level of agreement with scores being no more than one step apart was well above the benchmark value (Van Keer et al. 2017) at 93%, but the level of exact agreement remained below 50%. Against this background, we decided that the coders would perform consensus coding for all remaining data (a total of 546 scores). For scores where the coders had performed independent coding (prior to consensus coding), means were calculated and used on codes that differed between the coders (a total of 87 scores out of 140 scores that were independently scored by both coders).

Analysis of coded parent-child communication

Each dyad was analyzed separately. Descriptive statistics for RAACS and CBRS were calculated and the RAACS scores for the individual sessions were plotted for visual inspection. Combined means with a 95% confidence interval for RAACS items 1–7 (the minute-by-minute items) were plotted, as were the means for the two CBRS subscales.

Tau-U (Parker et al. 2011) was used to calculate effect size as between baseline and follow-up for both the RAACS scores and the CBRS scores. Tau-U is an approach to the analysis of single-case designs that measures the nonoverlap between phases combined with trends within phases; it is suitable for small datasets (Parker et al. 2011). Baseline-trend levels for baseline corrections were set in accordance with the descriptions given in Parker et al. (2011). In any interpretation of Tau-U results, account should be taken of the intervention, participants, and setting in question. However, a significant improvement of less than 0.2 may generally be considered a small change (Vannest and Ninci 2015). Hence this was applied as the threshold for change in the present study.

Coding and analysis of parental-interview data

The interview data were analyzed longitudinally using reflexive, thematic analysis (Braun and Clarke 2006,

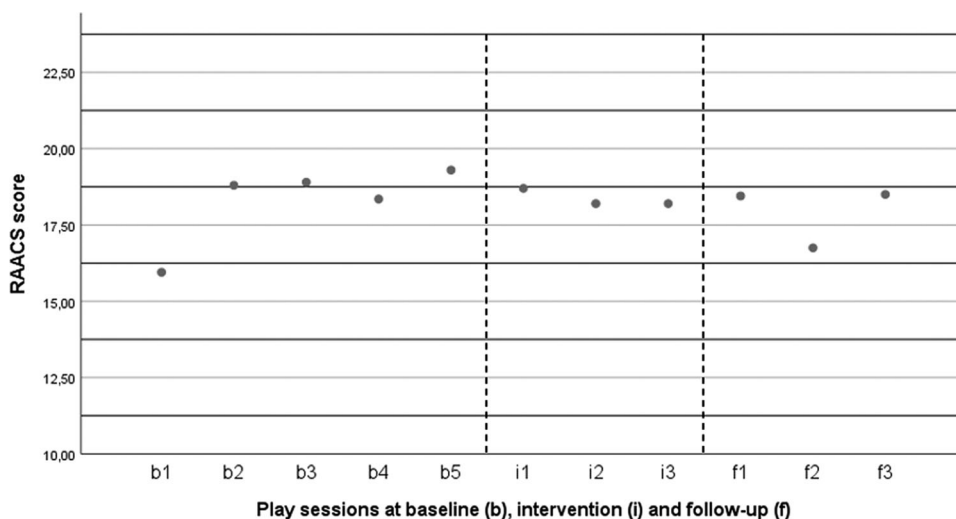


Figure 2. Jenny’s overall RAACS score per play session.

2019). In keeping with the description in Braun and Clarke (2006), the thematic analysis was analyst-driven and thus conducted as a theoretical, thematic analysis. Specifically, the analysis aimed to capture any narratives relating to partner responsiveness, AAC use, experiences of the child’s communicative attention and initiation, and experiences of the intervention process. The analytical procedure was performed mainly by the first author, who has extensive knowledge of the AKKtiv ComAlong course as well as long clinical experience of working with children with PIMD and their parents. The senior author was also actively involved in key steps of the analysis. The analysis followed a process described by Braun and Clarke (2006) that moves from familiarization with data over preliminary coding to preliminary themes and finally to a thematic structure. Throughout the reflexive thematic analysis, there was a constant shifting in focus between the transcribed data as a whole, smaller units of coded data, the codes, preliminary themes, and eventually final themes. The themes were also checked against the research questions. The longitudinal approach taken entailed a search for patterns of change as well as patterns of stability within the parents’ narratives.

Mixed-methods analysis

Statistical and thematic analytical procedures were carried out separately; their results are integrated in the Discussion section of the present paper, in accordance with the convergent mixed-methods design (Creswell 2015). Integration is performed using a narrative, weaving approach (Fetters et al. 2013) where each coded behavior is juxtaposed with experiences of change or stability relating to that behavior and experiences of factors having impacted that behavior.

Ethical considerations

Ethical approval was granted by the Regional Ethical Board of the Västra Götaland Region (case No. 166-17). Informed consent was obtained from the participating mothers and both parents of each child consented to the participation of the children. Owing to the developmental levels of the children, it was not possible to obtain an informed consent from them. However, the mothers were instructed to pay close attention to their children’s reactions during the recorded sessions and to stop a session if the child showed any sign of discomfort.

Further, the data-collection process was time consuming and both participating mothers signaled that they had difficulty finding the time for eighteen home visits (video recordings of play) as had originally been planned. For ethical reasons, the number of visits was reduced when a mother expressed a wish for this, although such reductions compromised experimental control.

Finally, the PIMD population is small and so heterogeneous that detailed descriptions might reveal the identity of a participant whose general area of residence is known. For this reason, the details given about participants have been kept to a carefully considered minimum. One example is that we have left out the ethnicity and first language of Sara and Sam, since that would risk revealing their identity.

Results

The results are presented case-by-case, starting with the analysis of coded parent-child communication (film recordings), followed by analysis of the mother’s description of the intervention process (interviews).

Results of video analysis of dyad 1: Jenny’s responsive communication style and use of AAC

Jenny’s mean RAACS score was 18.2 ($SD = 1.0$, min–max: 16.0–19.3) on the 23-point scale, where a higher

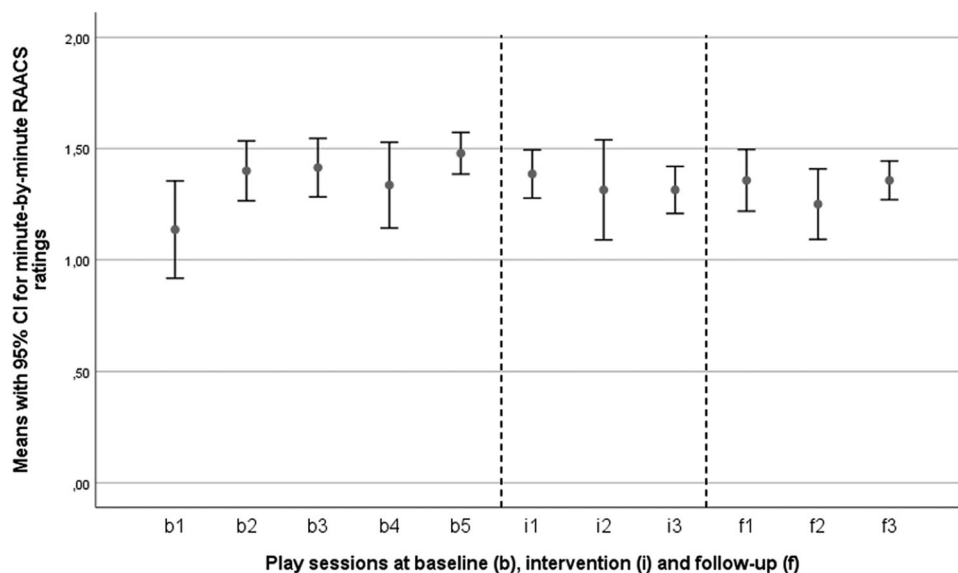


Figure 3. Jenny’s means per play session for the minute-by-minute ratings (a total of seven RAACS items).

Table 3. Results of Tau-U effect-size calculations comparing the baseline and follow-up phases regarding dyad 1 (Jenny and Hanna).

Participants	Dependent measure	Tau-U	p-value	CI (90%)
Hanna	attention	-0.44	0.36	-1 < > 0.35
	initiation	-0.05	0.89	-0.632 < > 0.53
Jenny	responsive communication style	-0.40	0.37	-1 < > 0.34

score indicates more AAC use and a more responsive communication style. RAACS scores per session are plotted in Figure 2 below; they indicate a pattern of stability throughout phases. Figure 3 shows plotted means for minute-by-minute ratings (items 1–7) with a 95% confidence interval. Tau-U calculations of effect size (see Table 3) confirm that there is no statistically significant difference in RAACS scores between baseline and follow-up.

Results of video analysis of dyad 1: Hanna’s interactive engagement

Hanna’s mean score on the *attention* component (items 1–4) of the CBRS was 2.85 ($SD = 0.92$, min–max = 1.25–5) while her mean score on the *initiation* component (items 5–7) was 2.22 ($SD = 0.55$, min–max = 1.33–3.33); higher scores indicate a higher level of interactive engagement. See Figures 4 and 5 for plotted means per session with 95% confidence intervals. Tau-U calculation of effect size revealed there to be wide confidence intervals and no statistically significant difference between baseline and follow-up for either component (see Table 3).

Results of thematic analysis of jenny’s interviews (dyad 1)

The analysis of Jenny’s interview data yielded one overarching theme and six subthemes broken down into two levels, as shown in Figure 6. In the following, each (sub)theme will be described and exemplified using

quotations (translated from Swedish by the authors) taken from the first, second, and third interviews (I1, I2, and I3, respectively).

My own development as a communication partner is a process

The overarching theme aimed to capture Jenny’s impression that the course had impacted gradually on her in a process-like manner. ‘AKKtiv [ComAlong] was just so self-evident and that’s been a process, too’ (I2). The course process primarily provided Jenny with knowledge and new ways of thinking. ‘I’m taking a lot home from the course. It made me think and gave me new ideas.’ (I2). In addition, the course process as such appeared to be situated within a larger process of Jenny adapting her communication to Hanna. As Jenny saw things, this larger process had started years before she participated in the course. ‘I’ve also thought about this communication thing, how you obviously can’t expect [Hanna’s other communication partners] to go through a process in a month when I’ve had many years to do so’ (I2). This idea of the course process belonging within a larger process is apparent in Jenny’s narrative about her course experiences, because those experiences are frequently connected to and compared with previous and parallel intervention experiences. In particular, Jenny related her course experience to her experience with a physiotherapist that worked with Hanna during her first years of life. In addition, Hanna was undergoing an AAC assessment

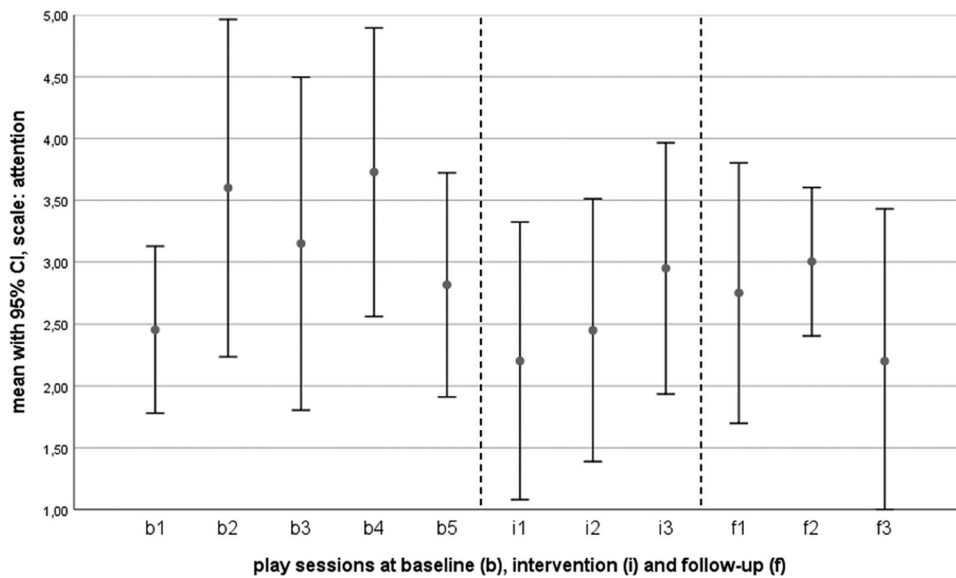


Figure 4. Hanna's mean score per session on the attention component of the CBRS.

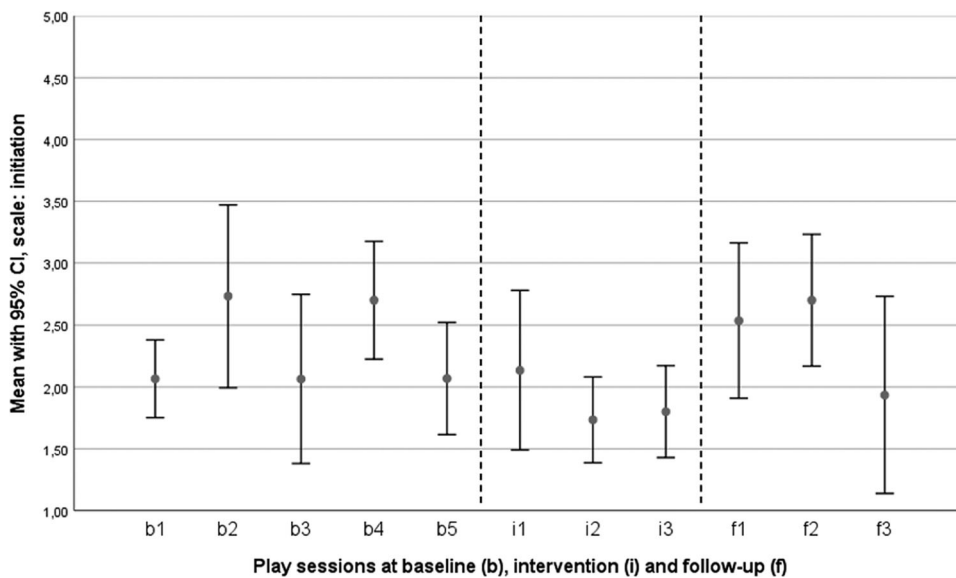


Figure 5. Hanna's mean score per session on the initiation component of the CBRS.

period at a regional AAC center while Jenny was attending the AKktiv ComAlong course. What is more, the daily communication support given to Hanna at home was affected by how the staff at her school supported and worked on her communication. Hence all of those experiences as well as the course and other previous communication interventions were all entangled in the process of Jenny identifying Hanna's communicative needs and adapting to them.

As seen in Figure 6, Jenny's experiences can be captured in six subthemes (broken down into two levels). All of these subthemes are not only connected to how Jenny experienced the course process as such but also related to the larger, ongoing process of her adapting her communication to Hanna.

The process requires time and reflection

Jenny repeatedly talked about the circumstances of interventions that had made it possible for her, as a mother, to truly change her ways of communicating with Hanna in order to stimulate Hanna's communicative development and provide her with better everyday communication opportunities. She mentioned this directly in relation to the course as well as in connection with other interventions received over the years. Jenny reflected on her own learning curve, which had included a stage of thinking and planning as a precursor to a stage of taking action. *'I'd been making notes about different ways of communicating and then I felt, 'now, I've actually done this already and I'm sort of finished with it'. Now I'm no longer there, now I'm*

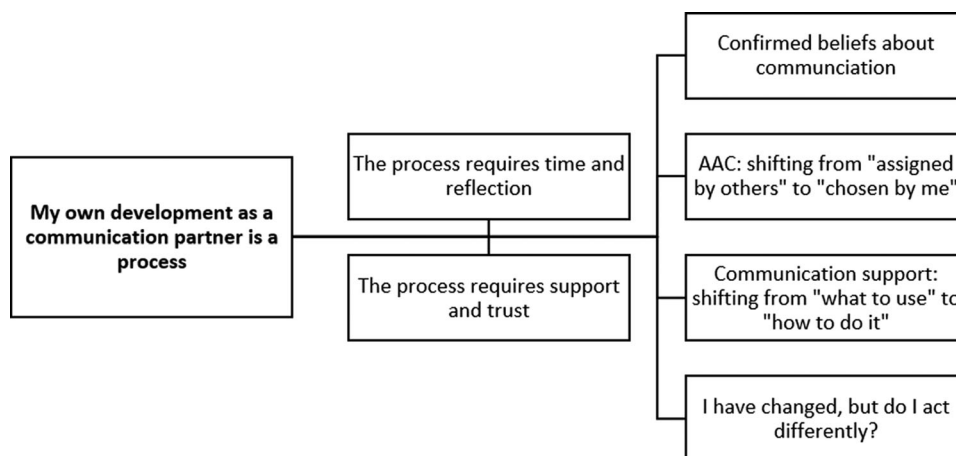


Figure 6. Thematic map illustrating the thematic analysis of Jenny's interview data: one overarching theme and six sub-themes broken down into two levels.

more in the actual doing.' (I3). Jenny considered that it was important to be able to talk about her and Hanna's communication at length and to reflect on this in detail, and that the time required for this had often been lacking in other interventions. 'It [another communication intervention] was proceeding quickly and I sort of couldn't keep up' (I3). When it came to the AKKtiv ComAlong course, by contrast, she found that the amount of time set aside for talking and sharing (both on her part and listening to the other parents' stories) generated reflection that, in turn, sparked change. Even so, she did not find that there was enough time to 'finish' the process of adapting her communication to Hanna – that work would have to continue after the course.' *But it's still very, very little time, even though we've had lots and lots of time [on the course] it's still really very little time.*' (I2).

In the interviews conducted after the course, Jenny also seemed to have gained a new perspective on what to seek from Hanna's SLPs. Before the course, she primarily referred to SLPs as persons providing her with AAC material. In the final interviews, she kept mentioning Hanna's SLP as someone she could discuss ideas about communication support with. The SLP thus seemed to have become a 'reflection partner' rather than solely a provider of material. *We talk a bit about how we're using this [AAC] now, like how we can do things. You know, I have some ideas, but you sort of need to brainstorm them a little and it feels like Lisa [a SLP], [...] it feels like she's open to talking about it'*(I2).

The process requires support and trust

Jenny kept coming back to the importance of the relationship with the interventionists. She had experienced a feeling of being scrutinized by interventionists. This had created a hierarchical relationship as well as some mistrust on both sides, which had negatively affected her courage to question and reflect, meaning that the interventions had rarely led to change. *Well, then*

[during an earlier intervention] you feel more like, or then you simply feel you're under scrutiny' (I2). By contrast, those interventions characterized by Jenny as really having affected her views on communication with Hanna (including the AKKtiv ComAlong course) were all led by interventionists who made her feel that they trusted her to have valid opinions about the intervention and made her feel supported in the performance of intervention tasks with Hanna. *And then [when interventionists ask for input from her] I feel like I have something to contribute, since, after all, I'm Hanna's mother, and then it feels kind of all free and good'* (I3).

Confirmed beliefs about communication

In the search for patterns of change as well as stability in the three interviews with Jenny, we identified stability in a number of beliefs connected to Hanna's communication abilities as well as Hanna's disabilities. Jenny did not seem to experience that the course challenged these beliefs about Hanna's communication, but rather that it confirmed them.

Firstly, Jenny kept referring to how the physiotherapist intervening with regard to Hanna's motor abilities during her preschool years had had a profound impact on Jenny's way of viewing Hanna as a competent communicator, making her realize that responsibility for quality interaction with Hanna rested with her communication partner. During physical therapy, this interventionist had set up rules for how Hanna should be communicated with (addressed directly, given enough time to answer, and being expected to answer). Jenny had assimilated these principles and tried to live by them ever since. Thus, when encountering the AKKtiv ComAlong course curriculum, with its strong focus on responsive communication strategies, Jenny immediately felt that this course connected to what she had already learned and what she held to be true and relevant. *And I took [what the physiotherapist taught me] home with me from that moment. Then it's just grown*

stronger, and on this course it's also just grown stronger too and I've been able to carry it with me.' (I2).

Another stable belief that Jenny mentioned repeatedly was how important it is to her to view Hanna first and foremost as a competent child rather than defining her by her disabilities or by her incompetence. Over the years, not all other communication partners or interventionists involved with Hanna had shared this perspective, sometimes causing Jenny to distance herself from them and from what they might have to offer. By contrast, she found this belief to be compatible with the AKKtiv ComAlong course curriculum and the course leaders, and this gave her confidence in the course.' *To me, [the course and its various learning activities] create an incredibly expanded image of, well, communication but also of the human being*' (I2).

A third belief that remained stable in Jenny's narratives during the interviews related to the need for Hanna's communication partners to adapt to her by communicating in very clear and concrete ways. Jenny emphasized this the strongest before the course started, but she kept mentioning it throughout the study.

AAC: Shifting from 'assigned by others' to 'chosen by me'

One identified pattern of change related to how, at the beginning of the study, Jenny tended to view AAC as something that others expected her to use but how she gradually shifted to seeing this as something that she chose herself and took charge of. When asked about AAC in the first interview, she mentioned AAC materials and methods that she knew of, almost like reciting homework. *'What else came to mind? Well, then there are (.) and there are also these situation-based boards.'* (I1). At that point, the family generally did not use the AAC she mentioned. Further, the AAC that Hanna had been introduced to during her preschool years had been used because interventionists had told the family to use it, not because the family believed in its potential for supporting communication. As soon as the family changed habilitation teams, they had dropped that AAC. *'At that point they were talking about Bliss and I felt that [...] that it [was] a bit abstract (...) but then we kind of went along with it, you know, as one does, and then when we got [to current habilitation team], it sort of faded out'* (I2). In the third interview, looking back on the past, Jenny concluded that she used to find AAC foreign and even frightening. In the second interview, she stated that she had decided to focus on AAC that she herself believed in, and she had started putting together a picture-based AAC for Hanna. In the final follow-up interview, Jenny felt comfortable with the AAC choices she made for Hanna. Indeed, Jenny seemed to have gained a sense of control. *'It's sort of like a process of liberation. Just because this [Jenny herself adjusting Hanna's picture-based vocabulary] is new territory, for*

both of us really, I think' (I3). At this point, Jenny also included AAC in a more detailed and clearer way in her vision of Hanna's future communication. What is more, in the third interview she had overcome her previous apprehension of high-tech AAC, which she used to reject. Looking back on her past experiences, Jenny found that only now did she understand what previous SLPs had aimed for when trying to implement AAC with Hanna. *'I understand [now] what the child-hab people and the SLPs were driving at and, you know, I may have seen it before but [then] I kind of couldn't see how I could approach Hanna in that way'* (I3).

Communication support: Shifting from 'what to use' to 'how to do it'

In the first interview with Jenny, the actual AAC materials—the physical objects—were in focus when she talked about communication interventions for Hanna. She may have particularly emphasized picture-based AAC, but she did not describe how that or any other AAC would fit into a broader communication context. The sole exception from this was manual signs, which she mentioned in all the interviews, discussing their potential relevance for attracting attention and supporting language comprehension. By contrast, in the second and third interviews, the subject of communication intervention included much more than the AAC materials themselves. *'That's right! There's been such a strong focus on what's really [...] producing things, doing this or that, but this idea of creating opportunities [for communication] [...]'* (I2). Jenny expressed that this was actually what she needed: knowing *how to use* the AAC materials—along with learning more about beneficial communication activities and strategies. *'It's actually the case that you need to go through this process of awareness. Then it's not just about acquiring a language, like sign language, or having picture-based communication, but then it's about, like I've had to do, reflecting on what I do and on what Hanna does. In this course, it's just as much about that, maybe even more.'* (I2). When looking back in the later interviews, Jenny also addressed how she had perceived past AAC interventions by SLPs as focused on the materials and lacking in support on how to use them. *'These [communication] boards and you child-hab people [...] you gave suggestions and that's terrific and all that, but then when [as a parent] you're left to your own devices, sort of, then it comes down to, well, you just have to get down to it.'* (I3).

I Have changed, but do I act differently?

Jenny had certain expectations of the course before attending it. Her most clearly articulated expectations were about obtaining an overall understanding of what Hanna needs in terms of communicative adjustment *'I hope to get some kind of [...] an overall approach to communication with Hanna, where I can also include these different parts and make it all into a whole, where*

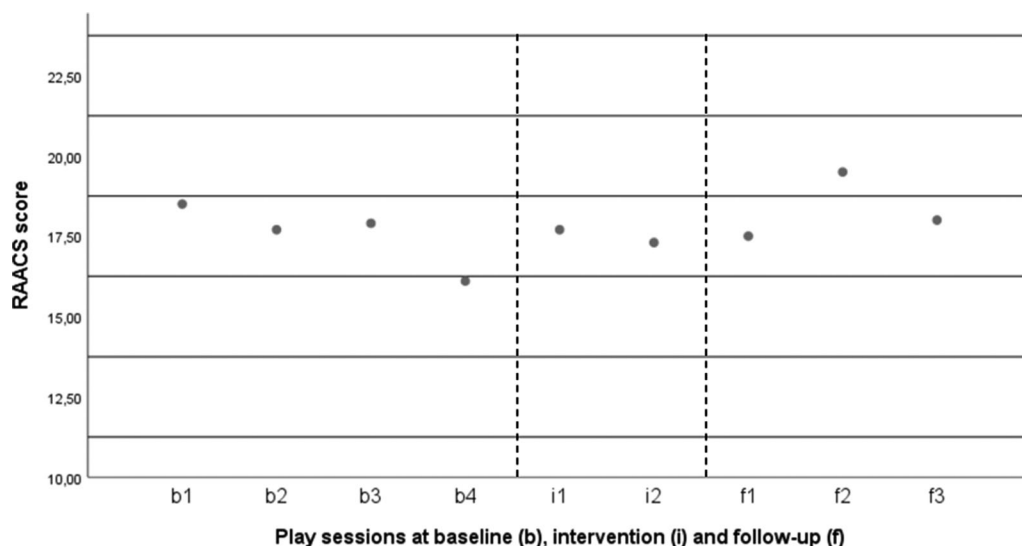


Figure 7. Sara's overall RAACS score per play session.

I can sort of easily show someone else.' (I1). She primarily seemed to aim for a type of knowledge and understanding that would include and combine both AAC and partner strategies. When asked after the course about how she thought it had affected her communication with Hanna, Jenny answered in line with her expectations, emphasizing the knowledge she had assimilated—her deep sense of knowing how to communicate with Hanna. *'Well, it's like, it's in every pore, in every cell that I've got, I kind of feel that I have [...] Well, just like you choose a certain language to speak to certain people, I feel that I know how to communicate with Hanna.'* (I2). However, it was not clear to Jenny whether her own observable behavior had actually changed as a result of the course. When asked whether she expected the filmed data to reveal any changes in the communication between her and Hanna, she mentioned that she might be more active in confirming Hanna's behavior as representing communicative actions. *'Then you should just sort of confirm her in that, and maybe I do that more now, I don't know.'* (I2). Further, Jenny suggested that she might have become clearer and more concrete in the way she expresses herself when communicating with Hanna. *'Maybe I've become even more concrete, I don't know, but that's hard to tell. [...] Maybe it's sort of easier for me to express myself in several areas, you know.'* (I2). When asked about the effects of the course one year afterward, she kept returning to internal change and to how she felt more sure about what she was doing, and why. *'Yes, but it felt so clear to me then, actually. That something was happening within me that made me think about what I was doing and I carried that with me.'* (I3).

Results of video analysis of dyad 2: Sara's responsive communication style and use of AAC

Sara's mean RAACS score was 17.8 ($SD = 0.9$, min-max = 16.1–19.5). Her RAACS scores per

session are plotted in Figure 7 (a higher score indicates a more responsive communication style and more AAC use). The average mean for the items measured minute-by-minute (items 1–7) are plotted in Figure 8 with a 95% confidence interval. No difference between phases is apparent from visual inspection, even though Sara's highest score occurred in the follow-up phase. As seen in Table 4, the effect size as measured using Tau-U is not statistically significant and the confidence intervals are very wide.

Results of video analysis of dyad 2: Sam's interactive engagement

Sam's mean score on the *attention* component of the CBRS (items 1–4) was 3.15 ($SD = 0.91$, min-max = 1.5–5.0). See Figure 9 for plotted means with 95% confidence intervals. His mean score for the *initiation* component (items 5–7) was 2.54 ($SD = 0.62$, min-max = 1.00–3.67); see Figure 10 for plotted means. Visual inspection of Figure 10 may suggest a negative trend during baseline (as lower scores indicate lower interactive engagement), but according to standard levels for baseline-trend control ($Tau-U > 0.4$ at baseline as well as in phase comparison, and both trends in the same direction), baseline-trend control was not relevant in this case (Parker et al. 2011). Effect-size calculations did not detect any statistically significant differences between baseline and follow-up for the CBRS measurements (see Table 4).

Results of thematic analysis of Sara's interviews (dyad 2)

The reflexive, thematic analysis of Sara's interview data yielded one overarching theme and three sub-themes (see Figure 11). In the following, each (sub)-theme will be described and exemplified using quotations (translated from Swedish by the authors)

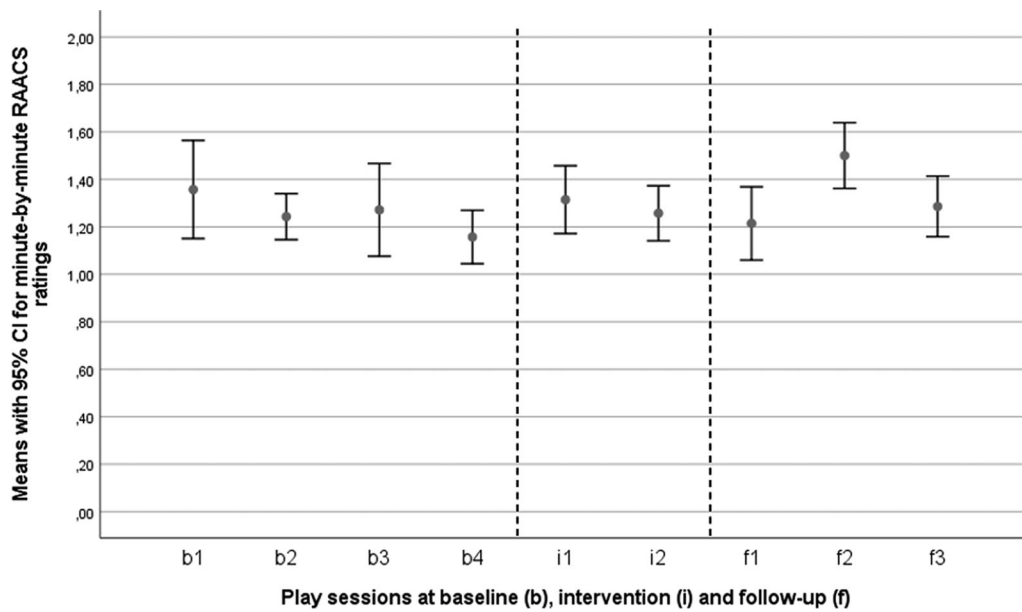


Figure 8. Sara’s means per play session for the minute-by-minute ratings (a total of seven RAACS items).

Table 4. Results of Tau-U effect-size calculations comparing the baseline and follow-up phases regarding dyad 2 (Sara and Sam).

Participants	Dependent measure	Tau-U	p-value	CI (90%)
Sam	attention	-0.65	0.11	-1 < > 0.02
	initiation	0.40	0.22	-0.14 < > 0.93
Sara	responsive communication style	0.33	0.48	-0.44 < > 1

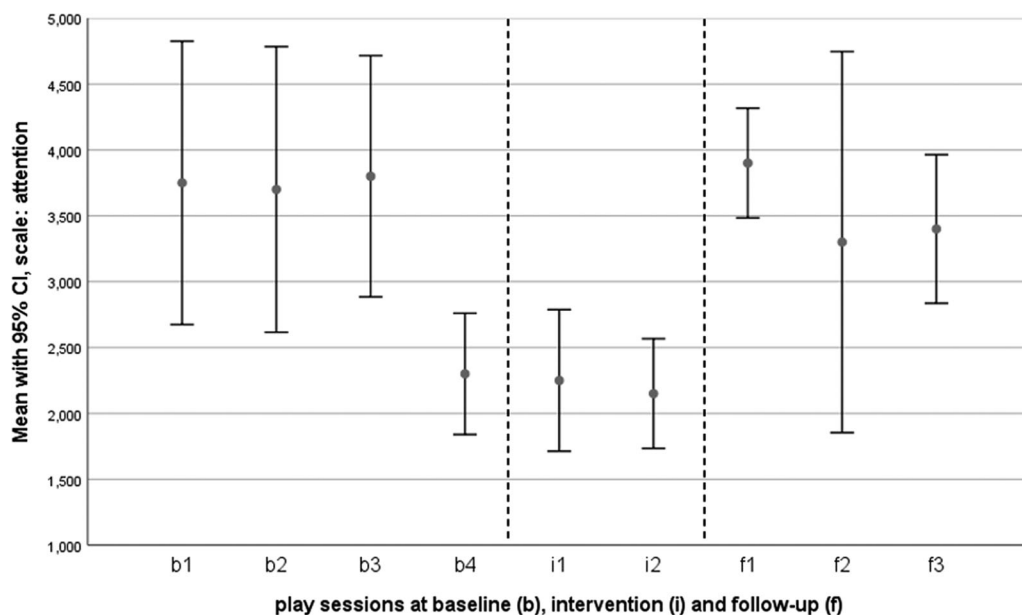


Figure 9. Sam’s mean score per session on the attention component of the CBRS.

taken from the first and second interviews (I1 and I2, respectively); note that Sara was not interviewed a third time one year after the intervention.

The course as a starting point

As far as Sara could remember, the AKKtiv ComAlong course was the first communication intervention offered to Sam. Prior to the course, the family had perceived that the habilitation services had focused primarily on

Sam’s gross motor development. ‘When it comes to communication in particular, I don’t think we’ve received any support targeting that, that I’ve received anything that has helped [...] specifically with communicating with him’ (I1). Sara had little by way of specific expectations of the content of the course apart from wanting to learn about communication. Further, she had no knowledge of AAC in general or of specific communication aids or methods available. When asked

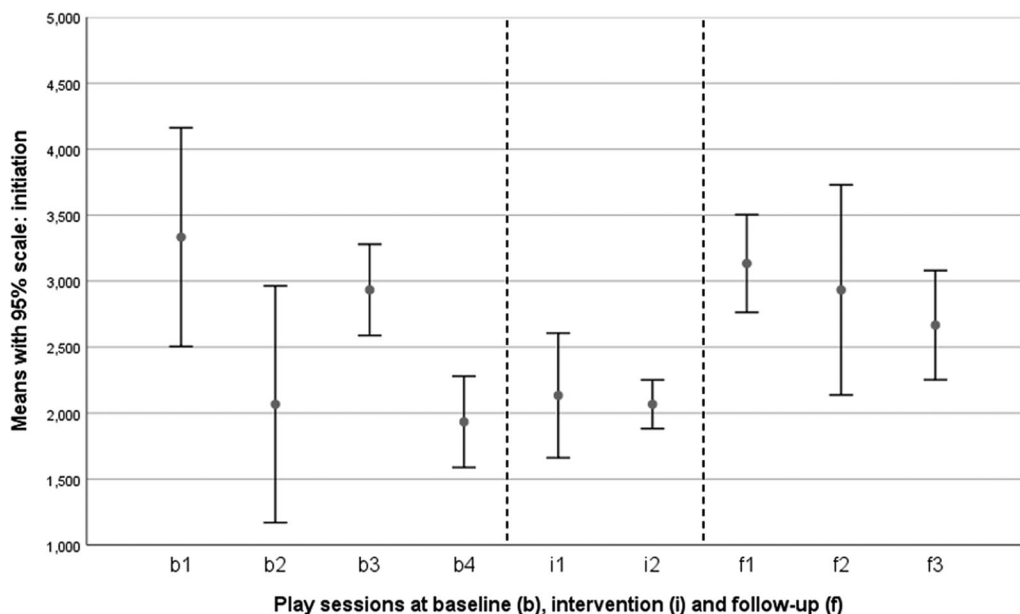


Figure 10. Sam's mean score per session on the initiation component of the CBRS.

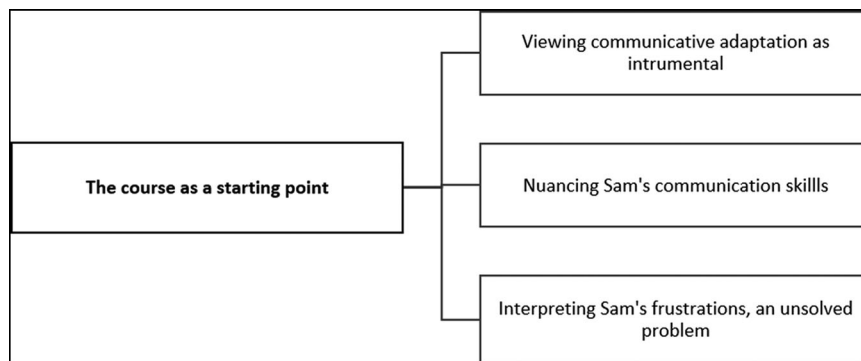


Figure 11. Thematic map illustrating the thematic analysis of Sara's interview data: one overarching theme and three subthemes.

whether she used any communication aids with Sam, she replied, 'Such as what?' (I1) and did not seem to have any preconceptions about communication aids. At the second interview, the course had introduced Sara to AAC. She had gained an overall knowledge of available AAC methods and tools, and she had started to visualize how some of them might be useful for Sam. 'This aid they showed [a speech-generating device], I've said I'm interested in it' (I2). She also seemed to have started experimenting with using more tactile cues. The habilitation services had scheduled a follow-up appointment after the course during which the parents were to participate in the drawing up of a communication-intervention plan. Sara was now motivated to work on Sam's communication and experienced a need for more knowledge and interventions. 'Well, it goes without saying that the course has been useful to me, but it's not enough' (I2). Further, Sam's parents had used a procedure during the course period whereby Sara (who was the one attending the sessions) and the boy's father had discussed each session, so that the father would be able to learn some of what the mother had learned. In that

sense, the course had made Sam's communication and his parents' adaptation to his communication a recurrent topic of conversation between the parents. To sum up the overarching theme, the course seemed to be catalytic in the sense that it made Sara (and the boy's father) conscious that there were opportunities to stimulate and facilitate Sam's communicative development and that it motivated them to obtain further support from the habilitation services as part of this process.

Viewing communicative adaptation as instrumental

In the first interview, Sara described how she would adapt to Sam's communication mainly in terms of providing him with information and visually interpreting situations for him. To her, many of the adaptations she made were based on his poor vision; she wanted to compensate in each situation for what he was unable to see. 'If an object is close at hand, I sometimes let him touch it and tell him what it is, otherwise I [just] tell him, like when we were at [a festival]. There were children there, painting, [...] and I told him 'here are some children who are painting, should we do that

too?’’ (I1). Sara was also very conscious about responding promptly to both Sam’s and his younger sibling’s signals, because she wanted them to feel safe and recognized, but at that point she did not seem to consider her prompt responses as supporting her children’s communication opportunities or communicative development. After the course, by contrast, Sara seemed to have gained a new outlook on her communication as instrumental in relation to Sam’s communicative development and his opportunities for more advanced communication. She took a very positive view of the communicative strategies taught on the course and trusted that Sam would benefit if she applied them. *‘Before the course I used to just talk and talk. I usually didn’t wait for him to answer. I liked this [new] way.’* (I2). Sara gave examples of how she applied the strategies in various everyday situations where they would fit both Sam and herself. She also mentioned that she had started talking *with* him—rather than *to* him.

Nuancing Sam’s communication skills

Before the course, Sara described Sam’s communication mostly in terms of his immediate reactions to what he experienced in the moment (mainly like or dislike) and in terms of his comprehending words or actions. *‘Sometimes I say the name of what we’re going to do and then he knows what it is even before it starts. Then he starts laughing, then he becomes happy’* (I1). In the second interview, Sara described Sam’s communication in a more nuanced and detailed way. She described how he initiated communication and how different sounds or facial expressions could bear different meanings. *‘Then he cries ‘Aaah’ [strong sound, fairly low chest-voice note]. Well, that means ‘come here.’* (I2). She also discussed ways for him to learn and develop communicative skills and words. Further, she emphasized that it had been important for her to learn that having the opportunity to express ‘yes’ or ‘no’ could be considered one of Sam’s communicative rights; she talked about how he did that in various situations. *‘That’s also a good thing I learned on the course, his right to say ‘yes’ or ‘no’ about things.’* (I2). Whether these more nuanced descriptions of Sam’s communication were sparked mainly by increased competence on his part, by new communication opportunities, or by a change in Sara’s perspective on communication was not always clear. Sara herself reasoned like this: *‘My thoughts have changed and the course has also allowed us to make small changes and he has developed’* (I2).

Interpreting Sam’s frustrations: An unsolved problem

Sam’s tendency to become upset, worried, or frustrated in situations outside of the home, coupled with his parents’ inability to calm him down and communicate with him in those situations, was an issue that Sara

talked about in both interviews. *‘Sometimes if we’re taking the tram he may start screaming and then [if] I know that he slept well, he ate, he took his medicines, I don’t understand what’s going on, why isn’t he comfortable? Then things get hard when he starts screaming and I can’t figure out the reason for it.’* (I1). In terms of ‘communication problems’ involving Sam, Sara identified such frustrations outside of the home as the most problematic situations. She did not think that the strategies and methods that she learned and applied during the course were helpful when it came to solving such situations. *‘Well, if you’re referring to the course, I didn’t receive or change anything from it’* (I2). However, she did take comfort in the fact that other parents on the course had described similar situations. *‘Well, they too talked about problems resembling the ones I experienced myself when the child gets angry or [...] Well, and you get the impression that your own son is not the only one who’s like that, there are others too.’* (I2).

Discussion

The present study aimed to identify possible changes in communication between children with PIMD and their parents after the parents had attended the PIMD-specific AKKtiv ComAlong course. Further, the study also aimed to compare quantitative measures of the parents’ and children’s communication with the parents’ reported experiences of the intervention process, and to investigate possible mechanisms underpinning any course-related changes seen in the communication between the parents and children. No changes were seen in the observed measures, but the parents provided information about their experiences of change and about their experiences of the intervention process that is of value in and of themselves and may also relate in interesting ways to possible undetected change in observed measures. We also believe that some important methodological and clinical insights were gained from the study.

Relationship between observed parent–child behaviors and parents’ experiences

In the following, the qualitative and quantitative results are integrated. The mothers’ experiences relating to their own responsivity and use of AAC as well as to their children’s interactive engagement are juxtaposed with and discussed in relation to the observed measures and the relevant literature.

Parental responsivity. No change in parental responsivity were seen in the coded video material. Both Jenny and Sara generally seemed to score relatively high compared with data from the reliability testing study of RAACS 4 (Lindberger 2020). This is in line with previous studies where both quantitative measures

(Van Keer et al. 2017) and qualitative analysis (Wilder and Granlund 2003) suggested that parents of children with PIMD generally might be sensitive and responsive in their communicative style, although generalizations to the larger population clearly need to be done with caution.

Jenny was unsure whether her communicative behavior in the filmed data would turn out to have changed. However, she was very clear that she *felt* differently about how she communicated with Hanna. The course content focusing on responsivity was highly valued by Jenny, which is in keeping with the sample of parents ($n = 22$) in the previous study of PIMD-specific AKKtiv ComAlong (Rensfeldt Flink et al. 2020). Jenny reported that it was very important to her, and seemingly motivating for her, first, to be confirmed in her conviction that the communicative behavior of the communication partner could constitute scaffolding and be augmentative to Hanna and, second, to feel secure in her knowledge about how to communicate with Hanna. Her statements such as *'Well it's like, it's in every pore, in every cell that I've got, I kind of feel that I have [...] I feel that I know how to communicate with Hanna.'* are evocative of Kruithof and colleagues' descriptions of 'embodied knowledge' in parents of children with PIMD (Kruithof et al. 2020). One possible interpretation is that the course helped Jenny feel confident in her already-embodied knowledge.

Sara mentioned several times that, as a result of the course, she actively waited for Sam's initiatives and responses, noting that this represented a behavioral change on her part. However, the RAACS scores analyzed did not show any difference in Sara's tendency to wait expectantly. It might be the case that, at baseline, Sara was naturally responsive (considering her overall high RAACS scores) but unaware of her behaviors. It is possible that the change she experienced was primarily due to an increased awareness of her own communication rather than to overt behavioral change. Here it is interesting to note that Sara explicitly mentioned being mindful of one responsive behavior—responding promptly—even before the course. However, the reason why she then considered prompt responses to be important was that she believed that they would make Sam feel safe and heard. The course made her ascribe additional value to responsive behaviors (including responding promptly) that related specifically to Sam's communication opportunities and communicative development.

Parental AAC use. In neither case did the analyses of video data show any increase in the mothers' use of AAC. In the case of Sara, she considered that the course had provided her with introductory knowledge of AAC and sparked an interest in it for the future and she had arranged for upcoming appointments with Sam's SLP to discuss this further. It is also worth noting that she was

absent from the course sessions that focused on 'hands-on' AAC application at home. In Jenny's case, her experiences were that the course (together with an AAC assessment that was taking place in parallel) had an impact on everyday AAC use at home. Judging from the findings of the thematic analysis, the course may have added motivation, inspiration, and knowledge about how to actually implement the AAC in everyday life. To Jenny, it seemed to be of the utmost importance that she experienced a sense of mutual trust and respect with the course leaders and that the course process, with its built-in elements of reflection, made it possible for her as a parent to digest information and try out new strategies at a comfortable pace. These experiences contrasted with other AAC interventions that the family had received earlier, and they were crucial to her engaging in and even taking charge of the application of AAC. Previous research has stressed the importance of ensuring that AAC interventions are based on collaborative relationships where the professionals are flexible and sensitive to the families' needs (O'Neill & Wilkinson 2020, Goldbart and Marshall 2004, Mandak et al. 2017, Moorcroft et al. 2020, Stephenson and Dowrick 2005) and that the parents' emotional needs in the AAC process are taken into consideration (Goldbart and Marshall 2004). Jenny's previous intervention experiences confirm a suggested gap between the insights about the importance of family-centeredness in AAC practice and the actual AAC service delivery (Mandak et al. 2017, Moorcroft, et al. 2020). When it comes to the absence of observed behavioral changes despite Jenny's reports of such possible changes, it should be noted that she characterized all of her communicative adaptation to Hanna as a process taking place in a stepwise fashion, with change first happening within her (changed thoughts) and only then possibly manifesting itself concretely in everyday communication with Hanna. It might be that the actual application of AAC mostly happened after the collection of video data. What is more, video data were collected only from one particular situation (play on the play mat in the living room) and it is not possible to know whether Jenny would have scored differently for AAC use if behavioral data had been collected from another everyday situation instead.

Children's interactive engagement. The analyses of child interactive engagement showed no increase, and nor did the parents make any clear statements to the effect that they considered the course to have increased their children's interactive engagement, even though both mothers found that their children had developed during the data-collection period. In this context it should be kept in mind that Sara's accounts of Sam's communication were much more detailed in the second interview than in the first one, including in terms of clearer descriptions of interaction engagement such as

initiation behaviors. This could be because Sam had grown more competent in these areas during the follow-up phase, but it could also be an effect of Sara's improved knowledge in the field of early communicative skills: she may simply have observed her son's communication with a 'sharpened eye.' Sara herself seemed to reason about mutual reinforcement between her changed thinking, her providing new opportunities for Sam, and Sam's development of new skills – a perspective on communication and communication development that actually is well in line with the dialogical and social-pragmatic view of communication that is the theoretical basis for the course (Rensfeldt Flink *et al.* 2020).

Limitations and methodological reflections

We sought to benefit from the potential of mixed-methods approaches when it comes to gaining a broader understanding of a research problem than sole reliance on either quantitative or qualitative methods would enable (Creswell 2015). It has been suggested that a combination of mixed-methods research approaches and single-subject research approaches is able to address a wide range of questions and to yield a comprehensive understanding of a case (Onghena *et al.* 2019, Hitchcock *et al.* 2010, Fetters *et al.* 2013). However, this is new ground being broken. We are not aware of any prior research that quantitatively monitored the communicative behaviors of parents and children with PIMD before, during, and after a communication intervention. Hence the quantitative part of the study presented us with several challenging methodological 'unknowns'.

Firstly, there is no gold standard with regard to outcome measures for intervention effect in such cases. In our study, the outcome measures were chosen based on previous research into parent-child interaction for children with PIMD as well as on the stated objectives of the AKKtiv ComAlong course curriculum. However, there was no way of knowing beforehand whether the instruments used would be sensitive enough to detect gradual changes in the communication between parent and child. Considering that Sara experienced an increase in her responsiveness, but no measurements confirmed that experience, it might be that RAACS 4 was not sensitive enough to detect small intervention effects in parents of children with such severe disabilities and slow development.

Secondly, the AKKtiv ComAlong curriculum aims to improve communication between parent and child in the context of everyday activities. For this reason, and for the sake of ecological validity, we wished to assess communication in a natural context. However, our observations were restricted to one specific situation in the home. Within that situation—play—the parents chose 'typical' activities that they believed both they and their children would enjoy, but we do not know to

what extent these communicative situations based on parental choice were representative of overall communication between parent and child.

Thirdly, it was not possible to know beforehand whether we had secured a stable baseline, and nor was it possible to control for the existence of a positive trend before moving on to the intervention—as generally required in single-subject experimental designs (Byiers *et al.* 2012). The reason for this is plain enough: behavioral coding using the RAACS and CBRS, including reliability checks, was far too time-consuming to be performed in parallel with data collection. We tried to deal with this challenge by having more than three baseline data points, which is the recommended minimum (Byiers *et al.* 2012). It should be noted that the Tau-U analyses subsequently performed did not reveal there to be any baseline trends in any of the measurements. In this context, the generally very wide confidence intervals surrounding the Tau-U values could also be highlighted. Adding more data points to the compared phases could potentially have decreased the large variability. On the other hand, when it comes to children with PIMD, their communicative engagement may naturally fluctuate largely over the day in a way that could be challenging when trying to capture trends over time.

Because of the nature of the course and the outcome measures (e.g. responsive communicative behaviors), it was not possible to withdraw the intervention studied to produce an ABA or ABAB single subject design: it was neither expected nor desired that the intervention effect would reverse (Byiers *et al.* 2012). Further, since the intervention was a clinically scheduled group intervention, it was not possible to control the starting date of the intervention, making a staggered intervention start impossible and hence ruling out a multiple-baseline design (Byiers *et al.* 2012). However, while an AB design can be referred to as pre-experimental in that it will not yield any certain findings with respect to causation, it is still useful for providing preliminary objective data regarding possible intervention effects (Byiers *et al.* 2012); since the intervention effects of PIMD-specific AKKtiv ComAlong represented a previously unexplored field, a pre-experimental, preliminary outcome was judged to be of interest. Indeed, the work was carried out against a backdrop of an almost complete absence of prior research into communication interventions in the PIMD population, meaning that the insights provided by the present study into methodological challenges and findings from quantitative results will be highly relevant for other researchers wishing to evaluate communication interventions for children with PIMD or other complex disabilities.

Implications for research and clinical practice

The preliminary search for observed intervention effect performed in the present study did not yield any results

that could be used for informing clinical practice. The small sample size, the measurement instruments used, and the implementation difficulties encountered may have restricted opportunities to understand the full potential of PIMD-specific AKKtiv ComAlong and any generalization of the results must be done with great caution. However, it seems clear that the course did have an impact on the participating mothers' *thinking* about communication with their children. Both parents mentioned 'inner changes' or 'changes to their ways of thinking' separately from actual behavioral changes. Jenny stated clearly that, in her case, inner change preceded behavioral change. This brings to mind the complex matter of the timing of effect measurements in parent-mediated interventions. Concretely, where it is expected that gradual changes to behaviors may occur long after an intervention has ceased, it would seem reasonable to assess quantitative measures over a lengthy period of time. What is more the effects of parent-mediated interventions intended to affect everyday communication between parent and child may have to be studied in a way that clearly acknowledges that those effects go well beyond the 'simple' learning and application of intervention strategies: parents need to go through a cognitive and emotional process involving changes to the patterns they use when reasoning about themselves and about their child. One lens that might usefully be applied in research within this field is that of transformative learning, with its focus on critical reflection about assumptions, beliefs, and worldviews as a guide to action and development for adult learners (Mezirow 2003, Mezirow 1997).

With all of the above caveats, it must still be said that the results of the present study—particularly those pertaining to Jenny and her daughter Hanna—corroborate the previously stated clinical implications for flexible, collaborative, family-centered AAC interventions (Moorcroft et al. 2020, Goldbart and Marshall 2004, Mandak et al. 2017, Ogletree and Pierce 2010, Stephenson and Dowrick 2005). Further, these results are also well in line with the claim by Kruithof and colleagues (2020) that it is crucial for professionals to listen to and value the 'embodied' expert knowledge held by the parents of individuals with PIMD, including by creating a space where those parents may share their knowledge. Another result that may be of clinical interest and may also spark a call for more research is that both mothers actually scored relatively high for responsiveness. This is well in line with previous studies of parents of children with PIMD (Wilder and Granlund 2003, Van Keer et al. 2017) but contrasts to other research suggesting that parents of children with disabilities that affect communicative behavior may be at risk of having a less responsive communication style (Warren and Brady 2007); clinically, it suggests a need for an approach where professionals build on existing

strengths in parents' communicative style and make parents aware of those strengths—rather than expecting there to be weaknesses in the parents' levels of responsiveness (as is not uncommon, judging from our own clinical experience).

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Conflict of interest

The authors report no conflict of interest.

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