

Supporting children with severe or profound learning difficulties and complex communication needs to make their views known:

Observation tools and methods

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All children have the right to shape the decisions that influence their lives (United Nations Convention on the Rights of the Child, 1989). Current policy frameworks in the United Kingdom (UK) emphasize the importance of involving young people with special educational needs (SEN) in the decisions that ultimately affect their education and wellbeing (e.g., UK Department of Education, 2014). For children to play a meaningful role in shaping these decisions, adults must be skilled at recognizing and discriminating communication bids by children. Facilitating children to contribute to decisions in this way can be accomplished by adults who recognize their communicative attempts and respond appropriately and consistently. The opportunity to contribute is crucial to the development of their autonomy (Nota, Ferrari, Soresi, & Wehmeyer, 2007). This can be a challenge for any child, but especially for children and young people with SEN, who often have speech, language, and social communication difficulties and who may not use traditional spoken means of expression (Cavet & Sloper, 2004).

Despite school staff being legally mandated to facilitate all children, regardless of their abilities, to participate in everyday decisions, there is little research on the extent to which children's experiences and perspectives are elicited in schools and the methods for doing so. This is particularly true of those who have intellectual disability and are pre-verbal<sup>1</sup> or who have emerging language skills (determined by the use of signs, spoken words or symbols), with often-idiosyncratic ways of communicating, requiring a skilled adult communication partner for interpretation (Ware, 2004).

In research settings, these children are often excluded by virtue of their limited communication and/or intellectual ability. One study, for example, reported the exclusion of 17 children who were pre-verbal, even though researchers had developed a range of creative

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<sup>1</sup> By 'pre-verbal', we mean a child or young person who can communicate intentionally (via verbal and nonverbal behaviors such as vocalizations, gestures or eye movements/gaze patterns), but does not yet use spoken words (or symbols) to communicate.

techniques to engage children in the study to communicate about their life aspirations (Rabiee et al., 2005).

One potential reason for the scarcity in seeking the views of children with intellectual disability and complex communication needs may be related to people's negative beliefs and low expectations of these children (Crombie, Sullivan, Walker, & Warnock, 2014; Milton, Mills, & Pellicano, 2014; Nind, Flewitt & Payler, 2010; Simmons & Watson, 2014; Sheehy & Nind, 2005). Another possible explanation relates to the challenges inherent in attempting to elicit the children and adolescents' views and experiences. Without a shared (spoken) language, educators can find it difficult to understand the distinctive nature of these children's communicative attempts, which can depend on context. There is also little work delineating the most effective ways to access these children's communicative behaviors across different learning contexts and to determine how their communicative attempts are interpreted and responded to by the people who know them well (Ware, 2004).

This multiple case study, therefore, focused on the utility of a set of tools to gain information about the communicative acts of children with severe-to-profound intellectual disabilities and complex communication needs in school. We present three case studies of such children, extending previous studies that have revealed the communicative acts of such children through the use of structured communication protocols and observational checklists (e.g., Brady, Marquis, Fleming, & McLean, 2004; DiStefano, Shih, Kaiser, Landa, & Kasari, 2016; Jones, 1989; Kiernan & Reid, 1987; McLean, McLean, Brady & Etter, 1991; McLean, Brady, McLean, & Behrens, 1999; Stillman & Battle, 1985). Using protocols and checklists, these previous researchers have provided detailed descriptions of children's communicative behaviors, demonstrating how features such as sustained communicative adult-child exchanges (DiStefano et al., 2016), children's gestural competence, and partner responsiveness can be predictive of positive language outcomes (Brady et al., 2004). These studies, however, were

not designed to investigate children's communicative behavior in naturalistic settings. Thus far, they have been unable to capture the evolving, dynamic relationship between a child and his or her communicative partner as it occurs in their day-to-day lives. To fill this gap, our study used a combination of observational and checklist measures to examine both the child's communicative acts (initiations and responses to the adults supporting them) *and* the supports provided by the adults during different learning contexts within a typical school day. Adults play a critical role in supporting the learning and communicative needs of these children. For example, one study investigated the nature of interactions between pre-school autistic<sup>2</sup> children or developmental delays and their teachers (Wong & Kasari, 2012). The researchers focused on how joint attention, which was defined as the sharing of attention between the child, another person and an object or event (Bakeman & Adamson, 1984), is fostered between children and adults in the classroom. Joint attention is a pivotal early-emerging behavior (at least in typical children), which can be used to express needs and preferences (Mundy & Gomes, 1998; Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006; see also Rollins, 2016, this issue). It also supports the development of more sophisticated communication skills (Charman et al., 2003; Kasari, Paparella, Freeman, & Jahromi, 2008; Loveland & Landry, 1986; Mundy, Sigman, Ungerer, & Sherman, 1986; Sigman & Ruskin, 1999). Wong and Kasari (2012) conducted two-hour structured observations in special education classrooms to examine children's engagement levels, joint attention, and play behaviors, as well as the extent to which teachers taught or prompted these skills. Children were given opportunities to initiate interactions that resulted in joint attention, but when children made more subtle bids for joint attention, by pointing or showing, these were not always acknowledged or reinforced as joint attention behaviors by their teachers. Crucially, Wong and Kasari reported that teachers often missed

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<sup>2</sup> Identity-first language is the preferred language of many people on the autism spectrum (see Sinclair, 1999) and their parents (Kenny et al., 2016). In this article, this led us to use the term *autistic* as well as person-first language to respect the wishes of all individuals on the spectrum.

opportunities to teach children actively both how to initiate bids for joint attention and how to respond to a teacher's bid for their attention. Moreover, on the few occasions when teachers did support children's responses to bids for joint attention, they tended to be testing comprehension or supporting answers to adult-directed questions rather than helping children to express themselves.

Another study (Nind et al., 2010) applied ethnographic methods to examine a wider range of the communicative behaviors expressed by children with intellectual disabilities and complex communication needs. These researchers sought to describe how communication partners supported these children. To do so, they presented case studies of three 4-year-olds to detail how the children's agency was affected by the structure and culture of the different "early years" settings the children attended. For one child (Mandy), Nind and colleagues showed how a particular communication partner fostered Mandy's sense of competence using multiple modes of communication. This partner was able to demonstrate the belief that Mandy could – and should – be able to make choices. For example, in one interaction, Mandy's adult communication partner took time to provide visual support, which enabled Mandy to make choices at her own pace. This success was contrasted with an observation in a different setting, which highlighted how gestural communicative acts may be missed by communicative partners. In this instance, Mandy's communicative act, which entailed reaching out for objects and signing "more," went unnoticed by the supporting staff. The researchers pointed out how an adult partner's failure to validate a communicative attempt ultimately reduced the number of successful interactions experienced by the child.

In these two studies, Nind et al. (2010) and Wong and Kasari (2012) demonstrated that adults have a fundamental role in either enhancing a child's communicative competence by reinforcing and facilitating communicative behavior, or hindering a child's development and autonomy by failing to recognize that communication has occurred or failing to provide the

appropriate support. These authors used different methods, including ethnographic (Nind et al., 2010) and structured observation methods (Wong & Kasari, 2012), to examine children's communicative exchanges and the way that adults attune to them by proactively adapting their own communication style and aspects of the environment. In the current study, we examined the utility of a *combination* of observational tools to understand the extent to which three children with severe-to-profound intellectual disabilities (called "learning difficulties" in the U.K.) and emerging language skills were able to express themselves and the extent and nature of adult support they received across a given day in their school.

First, we used ethnographic methods to capture the dynamic, evolving interactions that children who are pre-verbal or who have emerging language experienced with their adult communicative partners. Second, we used structured observations to produce a systematic record of the extent and nature of children's communicative behavior and adults' responses to them. These observations were further interpreted through the lens of the Social Communication, Emotional Regulation and Transactional Support (SCERTS®) framework (Prizant et al., 2006). SCERTS is an educational model that provides specific guidelines for helping a child become a competent and confident social communicator, while also identifying the necessary supports to be used by the child's communicative partners. Specific criterion-referenced checklists from the SCERTS framework enabled us to examine the range of communicative behaviors shown by the child and, importantly, the nature of the environmental (i.e., learning supports) and social adaptations (i.e., interpersonal supports) adopted by adults to support the children's communicative behavior.

We use these three case studies to illustrate (1) that children with severe-to-profound intellectual disability and complex communication needs have ways to make their intentions known, even though they may use idiosyncratic ways of doing so; (2) that adults play important roles in supporting these children's communicative bids; and (3) application of a set of

observational tools for gathering both qualitative and quantitative data concerning subtle and fine-grained nonverbal cues that might otherwise be overlooked.

## **METHOD**

### **Participants**

This research focused on three children (two girls and one boy) whose needs were considered so extensive that they received around-the-clock care for 52 weeks of the year. The children were enrolled in three different residential special schools in England. All children were in receipt of a Statement of Special Educational Need, which is a legal document that details a child's needs and the services that the local education authority has a duty to provide. One child (male; age 8) had an independent clinical diagnosis of autism and was described by staff to have severe learning difficulties (called *intellectual disability* in the US); two (both female; ages 11 and 13) were described as having profound learning difficulties. All three young people presented with complex communication needs.

These students formed part of a larger study on the views and experiences of children with special educational needs within UK residential special schools (Pellicano et al., 2014). Ethical approval for this study was awarded by a Research Ethics Committee UCL Institute of Education, University College London (approval number FCL 612). Information letters and consent forms were sent out to the parents of students in several classes of each school. Parental written informed consent was obtained for each of the three individuals who took part. Given the limited communicative abilities of these students, their assent was managed by monitoring their behavior and responses towards the researchers throughout the day (see Harrington et al., 2013; Cameron & Murphy, 2007). Pseudonyms are used to protect the students' identities.

### **Procedure**

A multi-disciplinary team including a speech and language therapist (called *speech-language pathologist* in the US), a research psychologist, and several educational psychologists

discussed in detail the tools and agreed on their application in this context. Both ethnographic methods and structured observations were used to capture adult-child interactions throughout the day, including activities within the school and residential settings. The SCERTS checklists were used to examine further children's wellbeing and the nature of the supports provided by the adults working with them.

***Ethnographic methods.*** One researcher, an educational psychologist, spent time with the young person from the beginning of the student's day, during educational lessons and break times, and after returning to the residential part of the school in the evening. In this way, she was able to capture a 'day in the life' of the young person living and being educated in school. This involved unstructured interactions with the young people, conversations with those around them, and at times, joining in the activities (e.g., accompanying young people on a trip or having dinner with them). This approach gave us an insight into their experiences and interactions with school staff, which in these cases, including teachers, teaching assistants, a physiotherapist and care staff.

The researcher took 'scratch notes' (notes made in the field including scribbles, notes, or small reminders), including information from informal discussions with staff throughout the day. These field notes were written up immediately after the school visit. They described the researcher's observations in detail, including the students' activities, their environments, the nature and degree of support given by others, and the amount of choice they were perceived to have during the day.

***Structured observation.*** We used a structured time-sampling technique to record simultaneously child-initiated and adult-initiated communication within discrete 60-second intervals for the duration of a single activity (e.g., eating breakfast, a school lesson, book time in the evening). Before each structured observation period began, the researcher recorded information regarding the activity in which the young person was involved, including who was



present and the extent to which she or he took part in choosing the activity. The researcher then coded the presence of child-initiated or adult-initiated communication within the 60-second interval, whether it elicited a response from the adult or child, and whether the bid for interaction led to brief reciprocal communication, defined as circumstances “where the child initiates and responds to bids for interaction for two consecutive exchanges ... with an exchange consisting of a turn from the child and a turn from the partner” (Prizant et al., 2006, p. 166).

***Observational Checklists.*** Once a student completed a single activity, the researcher completed four criterion-referenced observational checklists (described below) derived from the SCERTS framework (Prizant et al., 2006). This framework is a comprehensive, multidisciplinary approach to enhancing communication and social abilities of those on the autism spectrum and with related difficulties (Prizant, Wetherby, Rubin, & Laurent, 2003). Specifically, checklists from the “Social Partner stage, which largely represents the pre-symbolic stage of communication development, were used to document the range and frequency of communicative behavior used by each child during the period of observation (see Prizant et al., 2006). Information about the environmental adaptations (i.e., learning supports) and social adaptations (i.e., interpersonal supports) used by others during the observation period were also recorded (see below).

***The SCERTS Social-Emotional Growth Indicators Checklist*** examined the range of a young person’s communicative behaviors that, when combined, describe eight social-emotional growth indicators that reflect common priorities and concerns expressed by parents and professionals about autistic children. These include happiness, sense of self, sense of other, active learning and organization, flexibility and resistance, co-operation and appropriateness of behavior, independence and social membership, and friendships. Each of these domains is defined by clusters of five items describing a range of children’s communicative behavior. For example, the Happy domain is defined as “the capacity to experience, express and derive

positive emotion from everyday activities and engagement with partners” (Prizant et al., 2006, p.155). Example items include: Shares positive emotion using facial expressions and vocalizations, Greets, and Expresses happiness. The researcher rated the presence of these behaviors during a single activity.

*SCERTS Expression of Intentions and Emotions Worksheet* was used to record the presence of any expressive strategies used by the young person from a list of 16 operationally-defined socio-communicative behaviors (e.g., Requests desired food, Takes turns, Comments on object, and Expresses happiness). Whether the young person used pre-symbolic means (e.g., eye-gaze, facial expressions, reaching, showing, or waving) or symbolic means (e.g., delayed echolalia, sign language, or a picture system) also was recorded.

*The SCERTS Interpersonal Support checklist* was used to record the social or interpersonal supports. These are the strategies that adults use to adapt their communication style to suit a young person’s needs. This checklist included 33 criterion-referenced items, which relate to how a child’s communication partner can adapt his or her communicative style. These supports can be categorized into the following groups: being responsive to the child, fostering initiation, respecting a child’s independence, setting the stage for engagement, providing developmental support, adjusting the adult’s language input, and modeling appropriate behaviors.

*The SCERTS Learning Support checklist* was used to record environmental or learning supports, which represent the way the environment is organized to foster young people’s communicative competence. These supports comprise, for example, the use of Alternative and Augmentative Communication (AAC); the use of visual and organizational support; and the adjustment of goals, activities, and the environment in an attempt to foster active participation from the young person. The presence of any of these supports from a pre-defined list of 25 potential strategies was recorded.

### ***General Procedure***

Observations were made in an unobtrusive manner. The structured observation schedule was completed as soon as an activity (such as a breakfast routine, playtime or subject lesson) started, until the activity ceased. Immediately following the activity, the researcher completed the four SCERTS checklists. This process was repeated throughout the day, during different activities and interactions with different adults and across settings for each of the three participants and their communicative partners.

### **RESULTS**

Overall, the researcher spent a total of 27 hours with the students to understand how they spend a day in a residential school with the people who support them. Within this time, spent 9 hours and 33 minutes conducting structured observations across a range of 16 activities. In this section, we detail students' experiences during our observations on a case-by-case basis, using illustrative vignettes to identify their communicative attempts and the degree and nature of adults' responses to them.

To begin, we present information about the individual student's background, followed by summarizing results of the structured observations. Here, we focus on (i) the total number of bids made by the young person across the observed activities, (ii) whether these bids were responded to by the adult and (iii) whether any subsequent interactions were reciprocal in nature. We also examine the extent and nature of children's communicative acts as a function of activity, which we classified into three categories: instructional, recreational, caregiving. Next, we report the results from the SCERTS checklists, which describe the range of the student's communicative behaviors, evidence of his or her social-emotional well-being, and the number of social and environmental adaptations that the adults used across the structured observation. Finally, we present vignettes (two for each child) to illustrate the nature of the

child-adult interactions for two different activities and how successful the child was in making his/her views known.

## **Evie**

Evie is a 13-year-old girl with Rett Syndrome, who is non-ambulant and who has a history of epileptic seizures. She attended a school that catered for children and young people with profound learning difficulties and complex medical needs. At the time of this study, Evie had attended the school for 4 years. According to her parents, she is a sociable child, whose vocalizations are well understood by school staff. ‘School staff stated that they understood Evie’s preferences through eye gaze, vocalizations and sometimes reaching or touch, explaining, “they recognize them and they think, ‘yeah, this is just her being fed up, this is her in pain.’ It’s not very often where they think, ‘I’ve got no idea’.”

Teaching staff reported that Evie was working at P level<sup>3</sup> 3 and aspects of P level 4. At P level 3, pupils are described to be communicating intentionally, such as seeking attention through eye contact, gesture or action. They will be able to request events or activities, by reaching, for example. At P level 4, pupils are starting to use emerging conventional communication and can greet familiar people, initiate interactions and activities and respond to choices with actions, such as picking up one object over another (U.K. Department for Education, 2014).

One researcher spent a total of 12 hours with Evie, beginning the observation at 7am during the ‘home’ part of school. Evie then transitioned into school and was supported by school staff and a physiotherapist across group activities, including time in the hydrotherapy and sensory room. Structured observations were conducted for 5 hours and 9 minutes, across eight different activities including three home caregiving activities (breakfast, brushing teeth

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<sup>3</sup> In England, performance attainment targets (P scales) supplements the National Curriculum by specifying performance descriptors for children who are not able to access the national curriculum. The performance descriptors are used to describe the types and range of performance that pupils, may demonstrate when they are at an early developmental stage (U.K. Department for Education, 2014).

and dinner), four school instructional activities (hydrotherapy pool, art, ‘body bonanza’ and sensory lights) and one school caregiving activity (lunch) (range for each activity = 16 – 60 minutes). This particular school had an open door policy for family members to work with Evie throughout her day. On the day of the observation, Evie’s grandmother supported her during three school activities (see Table 1) in the afternoon until the end of the day when the observation ceased, at 7pm.

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***Child-initiated interactions.*** Over the course of the structured observations, Evie initiated communication 101 times (0.33 per minute) (see Table 1). The majority of these initiations (93%) were responded to by her communication partner, but just over one-third of these bids (36%) led to further reciprocal interaction.

Examination of Table 1 shows that the frequency of Evie’s communicative acts depended on the type of activity and who was her communicative partner (Evie’s grandmother versus school staff). Evie made 56 bids for communication (almost 1 per minute) during an hour-long Art session – where adults had offered both developmentally appropriate activities *and* offered her pieces of a banana to sooth her after she became unhappy – but she made many fewer initiations during other instructional or caregiving activities. School staff responded to all of Evie’s communicative bids during the home and school activities, but Art was also the only activity that generated reciprocal (child-staff) interactions.

Furthermore, across Activities 6, 7 and 8 for which Evie’s grandmother was her main communicative partner, Evie initiated communication 37 times (0.34 per minute). Her grandmother responded to the majority of these initiations (81%), and most of these (70%) led to an interaction that was reciprocal in nature. Across the five activities that were supported by

staff, Evie made 64 bids for communication (0.32 per minute). All of these bids (100%) were responded to by teachers and support staff but, interestingly, only eight of these interactions (12%) were deemed reciprocal.

***Adult-initiated interactions.*** Adults initiated a total of 128 interactions (0.41 per minute) with Evie across the 8 different activities (see Table 1) of which she responded to 98 of them (77%). Twelve of these interactions (9%) were reciprocal in nature. Of the 128 adult-initiations, staff members initiated the majority of these (92 bids), with 70 of these (76%) being responded to by Evie. Again, the activity that generated the most responses from Evie was Art. None of these, however, resulted in reciprocal interaction. By contrast, Evie's grandmother initiated the remaining 36 interactions across 3 activities, with Evie responding to the majority of them (78%). Most notably, just under one half of these interactions with her grandmother (43%) led to a reciprocal interaction.

***Range of communicative behaviors.*** Evie displayed an almost complete range of non-verbal social communicative behaviors to express herself, including eye gaze, facial expression, simple motor actions, crying, reaching, pushing away, showing, headshakes, nods and differentiated vocalizations (see Table 2). These were used for the purposes of behavior regulation, social interaction and expression of emotions, and communicating. She did not, however, demonstrate any joint attention behaviors with the intent of commenting on objects, actions, or events.

***Social Emotional Growth Indicators.*** Evie experienced activities that were generally supportive of her social emotional growth across the day. The highest social emotional growth scores (70%) were recorded during Art (see Table 1), which also elicited the greatest number of communicative exchanges. Conversely, her social emotional growth scores were rated to be the lowest (40%) when she was brushing her teeth, a 'must do' activity that potentially has little room for flexibility, choice and autonomy. The most variation across activities was found

within the active learning and organization domain, which related to Evie’s opportunities to problem solve and interact with her environment – areas that may be particularly difficult for adults teaching a child with Evie’s significant mobility challenges.

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***Supports used by adults.*** Across the entire 5-hour structured observation period, adults were observed to use a wide range of interpersonal supports (range = 21 – 30 of a possible 33) (see Table 1 for scores and Table 3 for examples). Similarly, adults were also observed to use a variety of learning supports (range = 10 – 20 of a possible 25), adapting the environment in a range of ways within individual activities.

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Insert Table 3 about here  
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Vignettes describing the researcher’s observation of Evie during two activities (Table 3) illustrate the significant challenges Evie faces in participating independently within an activity. She became disengaged at several points during the activities, either through a lack of available support and/or through her own difficulties expressing herself. Nevertheless, the resulting narratives paint a picture of a caring and responsive relationship between Evie and the adults who support her. Data obtained from the SCERTS checklists divide the nature of each interaction into its constituent parts – the nature of Evie’s communicative bids and the types of supports that adults used. In both activities, it was clear that adults were responding to Evie’s communicative needs, recognizing that both her eye gaze and vocalizations have communicative intent, and then acting accordingly. The nature and degree of support increased

during the activities, so that the adults supporting Evie responded consistently to her communicative behavior, with regard to making choices, sharing emotions, and protesting.

### **Adam**

Adam is an 8-year-old boy educated within a school that cares for children and young people with ‘the most severe and complex learning difficulties’. Adam has a diagnosis of autism spectrum disorder. Adam is energetic and ambulant. According to school staff, he can use a range of photographs and pictures to express his choices.

Adam was described to be working at P levels 3 and 4. P level 3 describes how a pupil can communicate intentionally by seeking attention and requesting activities. At P level 4, pupils are able to use a repertoire of objects of reference or symbols. They can use signs and/or symbols for familiar objects and communicate their likes and dislikes. Pupils working at P level 4 can respond to simple requests which contain one key word and can also understand that symbols convey meaning, by placing or choosing photographs, for instance (U.K. Department for Education, 2014).

The researcher spent 5 hours with Adam, during which his teacher provided one-to-one support. The observations began at breakfast, followed by a 1:1 sensory-based activity, a music session, and ended after Adam had finished his lunch. Of these 5 hours, structured observations of Adam were completed for 2 hours and 10 minutes across 3 different activities (see Table 4).

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***Child-initiated interactions.*** Over the course of the structured observations, Adam initiated communication 31 times (0.24 per minute). Most of these initiations (77%) were responded to by his communicative partner and the majority of these (67%) went on to become reciprocal interactions. The extent of Adam’s communication differed according to activity



(see Table 4), with his interaction during breakfast eliciting substantially more bids for communication during that time (0.48 per minute) than for the other two activities (0.17 per minute each).

***Adult-initiated interactions.*** Adults working with Adam initiated a total of 22 interactions (0.17 per minute), of which 18 (82%) were responded to by Adam. Only a minority of these interactions (11%), however, led to further reciprocal interaction in one (instructional) activity only.

***Range of communicative behaviors.*** Of the 16 behaviors detailed in the SCERTS intentions and emotions worksheet, the researcher observed Adam use 9 of these, including proximity, eye-gaze, facial expressions, crying, reaching, pushing away, spitting and the use of pictures (see Table 2). These were largely pre-symbolic, although he was able to use pictures to communicate his needs on one occasion. Adam did not demonstrate any behaviors with the intent of commenting on objects, actions or events during the observation session.

***Social Emotional Growth Indicators.*** Adam's scores were reasonably consistent across all activities (see Table 4). It is notable that, even in a lesson (Activity 3) that broke down (see Vignette 2, Table 5 for details), his social emotional growth was nevertheless rated as relatively high due to the nature of the strategies that his teacher used to re-engage him in the activity. When the adult provided respectful supports such as 'interpreting Adam's behaviors as communicative / regulatory', 'allowing him space and time to organize himself' and 'following Adam's interests and attention focus', Adam was rated highly in terms of sense of self, social membership and independence domains even though he scored less in active learning and cooperation.

***Supports used by adults.*** Across the structured observation period, the researcher observed adults use the majority of interpersonal supports outlined in the SCERTS checklist (range = 24 – 26 of a possible 33) (see Table 4 for scores and Table 5 for examples). Adults

were also observed using a large range of learning supports (range = 17 – 20 of a possible 25), making many adaptations to the environment within individual activities (see Table 5 for examples).

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In the illustrative vignettes described in Table 5, Adam was observed to be a young man with clear and often strong views about how he wanted to spend his time. This is evidenced across both activities through his communication of clear choices at breakfast time and through the intensity of his protests at school regarding horse riding. Differences in the type of adult supports during these two child-adult interactions are noteworthy. During breakfast, there were a range of visual supports enabling Adam to make a series of unambiguous, spontaneous requests. Later that morning during school time, the adults supporting him provided no visual supports – at least to begin with. Consequently, Adam’s communication attempts for this period were ambiguous. For example, he sat down when shown the horse-riding symbol. At this point, the class teacher attempted to repair this communication breakdown. He checked that Adam had understood what had been communicated to him by showing him a pair of riding boots, thus providing an alternative cue to the meaning of the original message. When this was met with similar refusals, he employed a range of sophisticated social and environmental adaptations to find out how Adam wanted to spend his time. The teacher selected a motivating activity, responding to Adam’s bid for joint attention, and allowing the activity to develop slowly. Finally, he created an opportunity for Adam to confirm that this was an activity that he wanted to continue.

**Leah**

Leah is an 11-year-old girl, attending a residential school supporting children and young people with profound learning difficulties. Leah is a twin, who was born at thirty weeks and shortly after birth, she contracted meningitis, which has had a lifelong impact on her development. Leah has profound and multiple learning difficulties, she is a wheelchair user and also has visual impairment. She is visited by her mother three times per week and by her father once a week. A member of her care staff described her as a ‘sociable’ and ‘happy’ girl. Leah is able to turn her head towards sounds that interest her and will smile and vocalize in response to an event that she enjoys. Leah is described by her mother as being socially aware and a person who often responds to familiar people with a smile.

Leah was assessed by school staff to be working at P levels 1 and 2. For pupils attaining these levels, they are described to encounter activities and experiences in a passive or resistant way and to show emerging awareness by having periods of alertness. This awareness may include focusing attention on certain objects and attending briefly in interactions with another person. Students at this level will start to respond consistently to familiar people, such as by smiling, and will engage in shared exploration and fully supported participation (U.K. Department for Education, 2014). The researcher spent 10 hours with Leah and collected 2 hours and 14 minutes of structured observational data across 5 activities, including a range of instructional, caregiving and recreational activities (see Table 6).

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Insert Table 6 about here

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***Child-initiated interactions.*** Over the course of the structured observation, Leah’s rate of communication was relatively low (0.17 per minute), with her initiating communication only 23 times over the 134 minutes of observation (see Table 6). Leah’s rate of communicative acts did not vary greatly between the different activities, with the exception of story time during

school, which elicited slightly more bids for communication from Leah (0.31 per minute). Adults responded to her bids for communication the majority of the time (70%). Only one (3%) of Leah's successful bids for communication, however, led to a reciprocal interaction.

***Adult-initiated interactions.*** Adults initiated many interactions with Leah during the observation (0.77 per minute), of which Leah responded to only a minority (4%) of them. None (0%) of these interactions, however, led to an interaction that was deemed reciprocal in nature.

***Range of communicative behaviors.*** Leah displayed fewer communicative behaviors than the two other children described herein, displaying only half of the behaviors described in the SCERTS intentions and emotions worksheet (see Table 2). Nevertheless, she was able to use eye gaze, facial expressions, crying, reaching, differentiated vocalizations and pushing away as a means to communicate with the adults supporting her. Like the other children, she did not demonstrate any behaviors that seemed to indicate a bid for shared attention on objects, actions, or events.

***Social Emotional Growth Indicators.*** Across the 5 observed activities, Leah's social emotional growth scores were commensurate with other parts of her observation. She scored the lowest of the 3 children achieving scores between 17 (43%) in the morning and 9 (23%) at the end of the day. Her scores reduced across the day, which staff suggested could be due to her feeling uncomfortable in her wheelchair. Across the 5 activities, the researcher recorded the highest scores in the 'happiness' domain (range = 5 – 2 of a possible 5). Leah's lowest scores were across the sense of self, independence and active learning domains but this may not be surprising, given her complex and significant needs and challenges with vision and mobility.

***Supports used by adults.*** Adults demonstrated a large range of interpersonal supports (range = 9 – 23 of a possible 33) and environmental adaptations (range = 5 – 15 out of a possible 25) (see Table 6). Note that 6 of these (organizational and visual) supports detailed in the

SCERTS checklist could not be employed with Leah due to her visual impairment. Nevertheless, it is noteworthy that the scores on the interpersonal and learning supports checklists were particularly low for the school storytime session (Activity 4) and, unusually, was an activity in which only 5 out of 12 (42%) of Leah's communicative bids were responded to. Information from notes made during the observation revealed that this activity involved a high proportion of spoken language and had potential for a wider range of environmental and social modifications to be used, which may have better facilitated Leah's engagement.

The vignettes illustrated in Table 7 describe a child whose levels of participation can vary dramatically across the course of a day. Data from the SCERTS checklists across the two activities clearly show that while Leah showed no observable communicative behaviors in the hydrotherapy pool, she nevertheless showed six different ways to communicate her wishes during the Gruffalo book-reading session (Activity 5). In the former case, the first vignette shows that the social and environmental adaptations made in the pool – namely securing Leah's attention, modelling activities and adjusting language – did not result in any communicative behaviors. By contrast, in the Gruffalo book-reading session, Leah was able to express a range of different emotions including happiness. Although there are seemingly a low number of supports used, the environment was structured to be motivating, predictable and repetitive, and Leah received responses to her communicative bids.

## **Discussion**

Previous studies (Nind et al., 2010; Wong & Kasari, 2012) have demonstrated that the relationship between children with intellectual difficulties and complex communication needs and the adults who support them is dynamic and transactional. Here, we implemented a set of tools designed to detail the nature and extent of children's communicative acts *and* the supports used by the adults working with them. The ethnographic methods, observational schedules and checklists allowed a fine-grained analysis of children's spontaneous communicative behavior

in naturalistic school and 'home' settings and of the way that these behaviors were recognized, interpreted and responded to by their communicative (adult) partners. The three case studies of children with severe-to-profound intellectual disability and complex communication needs clearly illustrate that they each had various ways to make their intentions known and that the adults supporting them recognized the majority of their bids for interaction – their often-idiosyncratic vocalizations, gestures and expressions.

Nevertheless, children's rates of bids for communication were low (Evie: 0.33 per minute; Adam: 0.24 per minute; Leah: 0.17 per minute). These estimates are in contrast to the rates of initiation documented by Shumway and Wetherby (2009) for much younger (18 – 24 month-old) autistic (M=1.23 bids per minute), developmentally-delayed (M=1.81 per minute), and typically developing (M=2.4 per minute) children. These rates are also lower than the rate of intentional communication acts measured by Brady et al. (2004) in younger, preverbal children (M= 2.74 bids per minute) of mixed etiology using the Communication and Symbolic Behavior Scales (Wetherby & Prizant, 1993).

Discrepancies in rates of initiations between studies may be related to sampling characteristics. The children observed herein appear similar in their rate of initiations to those described in McLean, McLean, Brady and Etter (1991) as 'contact communicators' (i.e., those who use communicative acts but make little use of words, signs, or conventional distal gestures) but dissimilar to those described in Brady et al. (2004) as 'distal communicators' (i.e., those who make use of a distal communicative act, such as pointing or eye contact with a person not in immediate contact with the participant). Although it is likely that the severity of the children's intellectual ability accounts for some of the differences between studies, it is particularly relevant that two children in our study had complex physical needs that may have prevented them from making, or from a communicative partner noticing, certain distal bids for communication relative to children with less severe difficulties.

Interestingly, and in keeping with the findings of McLean et al. (2000) and Brady et al. (2004), the structured observation schedule used in this study was effective in capturing a range of communication acts, including initiations and responses and showed differences both between and within individuals. For instance, the extent of some children's communicative bids during the observations varied according to context. Evie's rate of (child-initiated) communication during one particular activity -- Art -- far exceeded her rate for other activities. Importantly, the in-depth ethnographic work revealed why this was the case. Within Art, the adult was especially attuned to Evie's needs, presenting a range of developmentally-appropriate activities, meaningful interaction and food to soothe her when she became upset, thus increasing the range of communicative opportunities Evie enjoyed during this period.

The observations also revealed marked inconsistencies in the extent to which children's bids for interactions developed into a reciprocal exchange. Evie's grandmother and Adam's teacher developed 70% and 67% of children's communicative bids into a longer communicative exchange with several turn-taking sequences, whereas Leah and Evie's staff teams achieved only 8% and 4%, respectively. Understanding how children can be supported to engage in reciprocal interaction is important because these interactions play a critical role in the development of children's expressive language. In recent work, DiStefano, Shih, Kaiser, Landa and Kasari (2016) conducted a play and engagement-based intervention and found that the number of reciprocal interactions a child engaged with at baseline was positively associated with their development of language over the course of the 6-month intervention. Interestingly – and importantly for the current context – reciprocal interaction developed less often when adults initiated bids than when children initiated bids. When children initiate bids for interaction, this is thought to set the pace and tone for the adult to attune and respond to appropriately.

Differences across children with regard to reciprocal interaction could have resulted from differences in adults' degree of familiarity with the students and their often-idiosyncratic communicative and learning needs (see also Pellicano et al., 2014, Williams, 2005 and Wong & Kasari, 2012). Differences also could have resulted from variation in adults' confidence, experience, and expertise in working with children with severe-to-profound intellectual disabilities and complex communication needs. We observed a variety of staff working with the three young people – some were highly specialized (e.g., physiotherapist) while others may have received little training (e.g., teaching assistants). Unfortunately, we did not ask our adult participants to report on their level of training and experience. Future research should record adults' professional experience and their self-efficacy with regard to enabling children to communicate through social or environmental adaptations to examine whether these factors influence children's communication exchanges.

The combination of tools used here was sufficiently sensitive to identify the extent and nature of child-adult interactions that have been suggested by previous authors to be linked to positive language outcomes, including joint attention skills (Wong & Kasari, 2012), reciprocal communication (DiStefano et al., 2016), spontaneous expressive (prelinguistic) communication skills (National Research Council, 2001), especially distal points (Brady et al., 2004; McLean et al., 1999), and responsiveness in communicative partners (Baumwell, Tamis-LeMonda & Bornstein, 1997; Brady et al., 2004; Saxon, Colombo, Robinson, & Frick, 2000; Wetherby, Guthrie, Woods, Schatschneider, Holland, Morgan, & Lord, 2014). In particular, these methods, which were derived in part from the SCERTS framework (Prizant et al., 2006), showed that adults play an important role in supporting these children's communicative bids – both flexibly adjusting their behavior (interpersonal supports) and aspects of the environment (learning supports). For example, data from the checklists revealed that, for Evie, her communication partner needed to use a variety of both interpersonal and learning supports to



be responsive to her subtle bids for communication, whereas Adam's adult partner employed a range of learning supports in the form of AAC support and environmental adaptations. Yet, our data also showed that there was some variability in the extent to which adults used these supports, which again might be related to their familiarity with the child and/or their level of experience and expertise.

The results of this study have significant implications for current practice. The methods used in this study – the combination of rich ethnographic methods with structured observations and SCERTS behavioral checklists – revealed subtle and fine-grained nonverbal cues and supports that might otherwise be overlooked in autistic and non-autistic children who have the greatest learning and communication challenges. These methods could therefore be used as a reflective tool for practitioners to recognize the distinctive communicative acts of these children (see also Goldbart, Chadwick and Buell, 2014), to identify the way that they manifest socio-emotional wellbeing across the day, and to set individualized goals to increase engagement.

The total observation time presented here, however, might be difficult to implement in practice. Although it would certainly be possible to observe children for smaller time frames, our data (particularly from Evie's case study) nevertheless highlight the importance of observing the child across multiple activities and different communicative partners. Practitioners also might consider modifying the sampling time used in the structured observations. Here we used a 60-second interval but this could have been increased (e.g., to 120 seconds) without any significant loss of information given the particularly low rates of communication of these children.

The use of the SCERTS checklists might also be one way for educators to identify opportunities to support the child's communication and to identify improvements in the same adults' interpersonal and learning supports across multiple time points. In the current study,

such opportunities would include when Evie was left for breakfast, when Leah was in the hydrotherapy pool, and when Adam was experiencing communication breakdown. This approach should allow educators to build an individualized evidence base of support strategies for each child during specific activities and enable them to understand better which specific practices and support strategies are of benefit to individual learners (Goldbart et al, 2014). Indeed, one recent study has shown that the SCERTS model is promising in being able to support educators in promoting good practice and ways of working together as a team (Molteni, Guldberg, & Logan, 2013). Furthermore, this approach aligns with claims that standardized measures may not be appropriate for some populations (Chabon, 2012) and instead supports the need to understand an adult's role in facilitating how children learn (Imray & Hinchcliffe, 2014).

### **Limitations**

There are several limitations to this study. First, this study is necessarily limited by the small number of children who were observed, who also showed substantial variation in the nature of their difficulties, especially with regards to etiology. Although we observed the children intensely for a considerable amount of time across several different activities and communication partners, children with such complex difficulties often vary considerably from day to day both in their behavior and emotional wellbeing. Observing these children in a number of settings across several days – or weeks – might have strengthened the results.

Second, the observations were conducted by a single researcher and because they were not filmed we cannot establish the reliability of the measures used. This concern is especially related to the SCERTS checklists, which required the researcher to interpret children and adults' behaviors, rather than simply record them as in the structured observations. Indeed, interpreting the communicative behavior of young people with complex needs is an inferential process (Ware, 2004), a difficulty that applies for both researchers and communicative

partners. Future research could benefit from filming a portion of the observations – ideally taken across different days – both to establish the reliability of the coding scheme and checklists and to use the recordings as a reflective tool for practitioners. Ethnographic video recording raises ethical concerns regarding children’s privacy, however (Aarsand & Forsberg, 2010). Researchers should therefore balance the need for reliability with the need to maintain children’s privacy, especially since they are unable to provide informed consent.

## **Conclusion**

The views and experiences of children with severe-to-profound intellectual disabilities and complex communication needs are often neglected – both in research and in practice. Article 12 of the United Nations Convention of the Rights of the Child explicitly states that children have the right to participate in decision-making about their lives. Shier (2001), however, has noted this is “one of the provisions most widely violated and disregarded in almost every sphere of children's lives” (p. 108). For professionals working with children and young people with complex, severe, profound and multiple needs, this presents a considerable challenge. The techniques developed in this study show some promise in developing this aim.

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Table 1. The frequency of Evie's communicative acts and the range of supports provided by adults across the different activities.

	Activity 1	Activity 2	Activity 3	Activity 4	Activity 5	Activity 6 <sup>a</sup>	Activity 7 <sup>a</sup>	Activity 8 <sup>a</sup>	Total
<b>Type of activity</b>	Home caregiving	Home caregiving	School instructional	School instructional	School caregiving	School instructional	School instructional	Home caregiving	
<b>Specific activity</b>	Breakfast	Brushing teeth	Hydro-therapy pool	Art	Lunch	Body Bonanza	Sensory Lights	Dinner	
<b>Duration (minutes)</b>	52	16	32	60	40	32	20	57	309
<b>Structured observation: total number (rates per minute)</b>									Total (rate/minute)
Child-initiated interaction	4	0	3	56	1	20	5	12	101 (0.33)
Adult responded to child	4	0	3	56	1	20	5	5	94
Communication led to reciprocal interaction	0	0	0	8	0	20	5	1	34
Adult-initiated interaction	11	10	28	20	23	11	12	13	128 (0.41)
Young person responded to adult	5	6	18	20	21	11	10	7	98
Communication led to reciprocal interaction	0	0	0	0	0	11	0	1	12
<b>SCERTS Social Emotional Growth Indicators</b>									
Happiness /5	3	3	4	5	3	4	5	5	
Sense of self /5	3	2	2	4	3	2	2	2	
Sense of other /5	2	1	3	4	2	4	4	2	
Active learning & Organisation /5	2	0	3	1	4	1	1	1	
Flexibility and Resistance /5	2	2	2	3	2	2	1	1	
Cooperation / Appropriateness /5	2	3	4	4	2	3	3	2	
Independence /5	3	3	3	3	2	3	4	4	
Social Membership / friendship /5	3	2	3	4	3	3	4	4	
<b>Total out of 40 (%)</b>	<b>20 (50%)</b>	<b>16 (40%)</b>	<b>24 (60%)</b>	<b>28 (70%)</b>	<b>23 (58%)</b>	<b>22 (55%)</b>	<b>24 (60%)</b>	<b>21 (53%)</b>	
<b>SCERTS Interpersonal Supports Checklist</b>									
Responsive to child /8	7	7	8	8	7	7	5	8	

Fosters Initiation /4	3	1	2	4	2	2	2	3
Respects child's independence /4	4	4	2	4	2	2	2	3
Sets stage for engagement /4	4	4	3	4	4	4	4	4
Provides developmental support /5	2	1	4	4	3	2	3	4
Adjusts language input /3	2	2	1	3	1	1	3	3
Models appropriate behaviours /5	1	2	3	3	3	3	2	1
<b>Total out of 33 (%)</b>	<b>23 (70%)</b>	<b>21 (64%)</b>	<b>23 (70%)</b>	<b>30 (91%)</b>	<b>22 (67%)</b>	<b>21 (64%)</b>	<b>21 (64%)</b>	<b>26 (79%)</b>

#### SCERTS Learning Supports Checklist

Structures for active participation /5	4	2	5	5	5	5	4	4
Uses AAC <sup>b</sup> device to foster development /4	1	2	1	3	2	2	2	1
Uses visual/organisational support /6	3	2	2	3	3	3	2	1
Modifies goals/activities/environment /10	4	4	10	9	7	7	6	5
<b>Total out of 25 (%)</b>	<b>12 (48%)</b>	<b>10 (40%)</b>	<b>18 (72%)</b>	<b>20 (80%)</b>	<b>17 (68%)</b>	<b>17 (68%)</b>	<b>14 (56%)</b>	<b>11 (44%)</b>

Notes: <sup>a</sup>Communication partner was child's grandmother; <sup>b</sup> AAC: Augmentative and Alternative Communication

	Communicative intentions	Evie			Leah			Adam		
		Number of initiations	Pre-symbolic means	Symbolic means	Number of initiations	Pre-symbolic means	Symbolic means	Number of initiations	Pre-symbolic means	Symbolic means
<b>BEHAVIOUR REGULATION</b>	<b>Requests desired food or objects</b>	8	Eye gaze (shifting), crying, reaching, showing		2	Eye gaze (shifting), reaching, differentiated emotions		11	Eye gaze (shifting), reaching	Pictures, signs (clapping)
	<b>Protests/refuses undesired food/objects</b>	11	Facial expression, Tantrum, Headshake, Differentiated vocalisations, pushes away, head shake		2	Differentiated emotions		6	Eye gaze (shifting), facial expression, crying, pushing away, spitting	clapping
	<b>Requests help/other adaptations</b>		Eye gaze, Differentiated vocalisations, head nod, crying					2		
	<b>Protests undesired actions or activities</b>	30	Facial expression, crying, pushing away, head shake		5	Eye gaze (shifting), crying		1	Eye gaze (shifting), proximity, pushing away	
<b>SOCIAL INTERACTION</b>	<b>Requests comfort</b>	4	eye gaze, crying, differentiated emotions					1	Eye gaze (shifting), facial expression, reaching	
	<b>Requests social game</b>	9	Eye gaze, differentiated vocalisations							
	<b>Takes turns</b>				2	Eye gaze (shifting), reaching		5	Proximity, Eye gaze (shifting),	
	<b>Greets</b>	2	Eye gaze, facial expression, differentiated vocalisations,		3	Eye gaze, facial expressions		2	Proximity, Eye gaze (shifting), facial expression	
	<b>Calls Shows off</b>	5 1	differentiated vocalisation Eye gaze,							
<b>JOINT ATTENTION</b>	<b>Comments on object</b>	0			0			0		
	<b>Comments on action or event</b>	0			0			0		
<b>EXPRESSION OF EMOTIONS</b>	<b>Expresses happiness</b>	13	Eye gaze, Facial expression, differentiated vocalisations, simple motor actions (clapping)		3	Eye gaze (shifting), facial expressions, differentiated emotions		2	Eye gaze (shifting), facial expressions	
	<b>Expresses sadness</b>	9	Eye gaze, Crying, facial expression, differentiated vocalisations		2	Facial expressions, differentiated emotions		1	Eye gaze (shifting), facial expressions	
	<b>Expresses anger</b>	5	Crying, pushing away, Facial expression, differentiated vocalisations							

<b>Expresses fear</b>	4	Facial expression, differentiated vocalisations	4	Crying, differentiated emotions	
<b>TOTAL</b>	<b>101</b>		<b>23</b>		<b>31</b>

Table 2. *The range and function of spontaneous communicative behaviours for each child.*

Table 3. *Vignettes describing two observed activities with Evie, including both the nature of her communicative bids and the strategies used by adults to support her.*

Ethnographic Data	SCERTS® checklists	
Narrative	Evie's communication	Adult Supports
<b>Vignette 1</b>		
<p><b>Breakfast.</b> At 7.30am, Evie was awake, dressed and watching television in the lounge. She was alone and had a mouthful of Weetabix, which she was not chewing. After eleven minutes of holding it in her mouth, she started pushing her Weetabix out so that it fell on to her chin. Evie looked towards me and held eye contact. She started to struggle to wipe her face and made short vocalisations. In response to this, I took a towel and helped Evie to clear the food from her face. I then left to find staff to inform them that Evie required support.</p> <p>When staff arrived, they tried to persuade Evie to continue eating by feeding her the Weetabix, however Evie turned her head away. A staff member chatted casually to her and asked, "What else shall we try?" The staff member explained that they have three options for breakfast, so that Evie could choose what to eat. After</p>	<p>Looks towards people Requests help when frustrated Responds to sensory and social experiences with differentiated emotions</p> <p>Protests undesired actions or activities</p>	<p>Follows child's focus of attention</p> <p>Responds appropriately to child's signals to foster a sense of communicative competence</p> <p>Adult offers choices</p>

<p>waiting for Evie to turn her head, the adult offered yoghurt, which she accepted. She then modelled to Evie how to hold her drink, to help her understand that this was what she was asked to do. Evie was then able to do this for a short time. The staff member also opened her own mouth and softly touched Evie's mouth asking "can I just have a look?" to check whether she had swallowed her food.</p>	<p>Makes choices when offered by partners</p> <p>Anticipates another person's actions within a familiar routine</p> <p>Responds to bids for interaction</p>	<p>Attunes to child's emotion and pace</p> <p>Provides guidance for success in activities</p>
<p><b>Vignette 2</b></p>		
<p><b>2pm, school.</b> When Evie joined her class, she seemed unhappy. Firstly, she started to make sharp, small noises, but these progressively became longer and louder and then she started to cry. The staff member working with Evie was empathetic towards her: "What's the matter? I know, I know", "Did you not like coming out of the pool?" Evie continued crying for 19 minutes. For part of this time the member of staff walked her around the school for a "change of scenery", reporting that Evie sometimes enjoyed this. She also brushed Evie's hair to try to soothe her.</p>	<p>Protests undesired actions or activities</p> <p>Responds to sensory and social experiences with differentiated emotions</p> <p>Soothes when comforted by partners</p> <p>Uses appropriate rate of communication for context</p> <p>Responds to bids for interaction</p>	<p>Recognises signs of dysregulation and offers support</p> <p>Offers break from interaction or activity as needed</p> <p>Recognises and supports child's behavioural strategies to regulate arousal level</p> <p>Facilitates reengagement in interactions and activities following breaks</p> <p>Uses appropriate proximity and nonverbal behaviour to encourage interaction</p> <p>Imitates child</p>



<p>On return to the class, Evie’s class teacher focused his attention on comforting her. He pulled a chair next to her and imitated her vocalisation, which became a brief reciprocal interaction between them. She looked closely at his face during this time.</p> <p>Her class teacher wondered aloud whether Evie was hungry, and held a banana out to her saying, “Hmm, banana?” The teacher waited for a response from Evie, who smiled after a short pause. During this time, Evie’s teacher sat next to her. They made eye contact for extended periods of time whilst Evie was eating.</p>	<p>Engages in extended reciprocal interaction</p> <p>Shares positive emotion using facial expression and vocalisations</p> <p>Looks towards people</p>	<p>Creates turn taking opportunities and leaves spaces for child to fill in</p> <p>Offers choices non verbally</p> <p>Provides time for child to solve problems / complete activities at own pace</p> <p>Responds appropriately to child’s signals to foster a sense of communicative competence</p> <p>Uses appropriate proximity and nonverbal behaviour to encourage interaction</p>

Table 4. The frequency of Adam's communicative acts and the range of supports provided by adults across the different activities.

	Activity 1	Activity 2	Activity 3	Total
<b>Type of activity</b>	Home	School	School	
	caregiving	instructional	instructional	
<b>Specific activity</b>	Breakfast	Child-led outside activity	Learning	
<b>Duration (minutes)</b>	29	53	48	130
<b>Structured observation</b>				Total (rate/minute)
Child-initiated interaction	14	9	8	31 (0.24)
Adult responded to child	14	5	5	24
Communication led to reciprocal interaction	8	3	5	16
Adult-initiated interaction	7	8	7	22 (0.17)
Young person responded to adult	6	6	6	18
Communication led to reciprocal interaction	0	0	2	2
<b>SCERTS Social Emotional Growth Indicators</b>				
Happiness /5	5	5	4	
Sense of Self /5	3	3	4	
Sense of other /5	3	2	2	
Active learning and Organisation /5	4	3	2	
Flexibility and Resistance /5	2	4	3	
Cooperation / Appropriateness /5	2	3	2	
Independence /5	4	5	4	
Social Membership / Friendship /5	4	3	3	
<b>Total out of 40 (%)</b>	<b>28 (70%)</b>	<b>28 (70%)</b>	<b>24 (60%)</b>	
<b>SCERTS Interpersonal Supports Checklist</b>				
Responsive to child /8	8	7	7	

Fosters Initiation /4	4	3	3
Respects child's independence /4	3	4	4
Sets stage for engagement /4	4	4	4
Provides developmental support /5	2	3	4
Adjusts language input /3	2	2	2
Models appropriate behaviours /5	1	3	1
<b>Total out of 33 (%)</b>	<b>24 (73%)</b>	<b>26 (79%)</b>	<b>25 (76%)</b>

**SCERTS Learning Supports Checklist**

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Structures for active participation /5	5	5	5
Uses AAC <sup>a</sup> device to foster development /4	2	3	3
Uses visual/organisational support /6	4	4	4
Modifies goals/activities/environment /10	6	8	8
<b>Total out of 25 (%)</b>	<b>17 (68%)</b>	<b>20 (80%)</b>	<b>20 (80%)</b>

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Notes: <sup>a</sup> AAC: Augmentative and Alternative Communication

Table 5. *Vignettes describing two observed activities with Adam, including both the nature of his communicative bids and the strategies used by adults to support him.*

Ethnographic Data	SCERTS® checklists	
Narrative	Adam's communication	Adult supports
<b>Vignette 1</b>		
<p><b>Breakfast.</b> Adam had his own breakfast menu that had been individually designed for him with photographs of a range of food and drinks. The teacher placed the pictures around him on the table and immediately after these were laid out, Adam chose a picture of cranberry juice and gave it to his teacher.</p> <p>The teacher left the table to pour the cranberry juice then held it in front of Adam, with the photograph, and stated; "Here's your cranberry juice". Adam then tapped the picture and the juice was given directly to him. Using this method, Adam also chose toast and Nutella.</p> <p>While waiting for the breakfast, Adam looked at his teacher, moving his head closer to the teacher and looking directly into his eyes. Adam repeated this 5 times. Each time his teacher reciprocated and copied his movement,</p>	<p>Makes choices when offered by partners</p> <p>Looks towards people</p> <p>Makes choices when offered by partners</p> <p>Looks towards people</p> <p>Engages in extended reciprocal interaction</p>	<p>Uses AAC<sup>a</sup> to foster communication and expressive</p> <p>Responds appropriately to child's signals to foster a sense of communicative competence</p> <p>Uses AAC to foster communication and expressive language</p> <p>Uses appropriate proximity and nonverbal behaviour to encourage interaction</p> <p>Imitates child</p> <p>Responds appropriately to child's signals to foster a sense of communicative competence</p>

<p>with a smile and sometimes with a nod of the head. After Adam had eaten this, he reached for his book, turned the page and chose cereal and toast. The teacher responded that he needed to choose just one of these. To support Adam's understanding of his expectations, the teacher held both pictures up in front of Adam. He chose the cereal. He was then shown pictures for options to put on his cereal and chose honey.</p>	<p>Responds to visual cues</p> <p>Makes choices when offered by partners</p>	<p>Uses AAC to foster understanding of language and behaviour</p>
<p><b>Vignette 2</b></p>		
<p><b>10:05pm, school.</b> When Adam was ready to leave his room, his teacher asked him to go outside by placing a symbol on his choosing book that represents horse riding.</p> <p>Adam seemed to have decided that he didn't want to go; he sat on the floor in the lounge and spat when his teacher came near him. The teacher felt that Adam needed time to calm down and after 10 minutes, when he had stopped spitting, the teacher entered the room and tried again. This time he used an object of reference, Adam's riding boots, but he received the same response. The teacher retreated from the room again, left Adam for a further</p>	<p>Protests undesired actions or activities</p> <p>Protests undesired actions or activities</p> <p>Looks towards people</p>	<p>Uses AAC to foster understanding of language and behaviour</p> <p>Interprets problem behaviour as communicative and/or regulatory</p> <p>Uses AAC to foster understanding of language and behaviour</p> <p>Interprets problem behaviour as communicative and/or regulatory</p> <p>Honours protests, rejections and refusals when appropriate</p> <p>Infuses motivating materials into activities</p>

<p>3 minutes and then tried another activity.</p> <p>The teacher entered the room and went straight to a cupboard, pulling out a massage box. Adam didn't spit this time and looked at what his teacher was doing. The teacher pulled a chair behind Adam and indicated for Adam to move closer, by tapping the floor in front of him. Adam did this. Adam then held out his hand towards his teacher, to which his teacher said, "You want me to massage your hand?" and started to do so. After a minute, the teacher stopped and asked, "Do you want more or are you finished?" Adam clapped his hands, which staff interpreted to mean more and the massage continued.</p>	<p>Re-engages in interaction or activity after recovery from extreme dysregulation</p> <p>Anticipates another person's actions within a familiar routine</p> <p>Uses conventional distal gestures (wave, reach, point, clap, head shake, nod)</p> <p>Makes choices when offered by partners</p>	<p>Uses appropriate proximity and non-verbal behaviour to encourage interaction</p> <p>Responds appropriately to child's signals to foster a sense of communicative competence</p> <p>Creates turn taking opportunities and leaves for child to fill in</p> <p>Responds appropriately to child's signals to foster a sense of communicative competence</p>
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Note: <sup>a</sup>AAC: Augmentative and Alternative Communication

Table 6. The frequency of Leah's communicative acts and the range of supports provided by adults across the different activities.

	Activity 1	Activity 2	Activity 3	Activity 4	Activity 5 <sup>a</sup>	Total
<b>Type of activity</b>	Home	School	School	School	Home	
<b>Specific activity</b>	caregiving	instructional	instructional	instructional	recreational	
<b>Duration (minutes)</b>	Morning routine	Good morning song	Hydrotherapy	Story time	Gruffalo book	
	40	8	18	39	29	134
<b>Structured observation</b>						Total (rate/minute)
Child-initiated interaction	8	1	0	12	2	23 (0.17)
Adult responded to child	8	1	0	5	2	16
Communication led to reciprocal interaction	0	1	0	0	0	1
Adult-initiated interaction	37	4	26	15	21	103 (0.77)
Young person responded to adult	4	4	10	4	4	26
Communication led to reciprocal interaction	0	0	0	0	0	0
<b>SCERTS Social Emotional Growth Indicators</b>						
Happiness /5	5	4	4	2	2	
Sense of Self /5	0	1	0	0	0	
Sense of other /5	3	2	2	1	1	
Active learning and Organisation /5	0	0	0	0	0	
Flexibility and Resistance /5	3	1	3	1	1	
Cooperation / Appropriateness /5	2	2	2	2	2	
Independence /5	1	0	0	0	0	
Social Membership / Friendship /5	3	3	2	3	1	
<b>Total out of 40 (%)</b>	<b>17 (43%)</b>	<b>13 (33%)</b>	<b>13 (33%)</b>	<b>9 (23%)</b>	<b>7 (18%)</b>	
<b>SCERTS Interpersonal Supports Checklist</b>						
Responsive to child /8	5	6	5	2	5	

Fosters Initiation /4	1	2	4	0	1
Respects child's independence /4	1	0	2	0	0
Sets stage for engagement /4	4	4	4	4	4
Provides developmental support /5	2	3	3	0	2
Adjusts language input /3	3	2	2	1	2
Models appropriate behaviours /5	2	2	3	2	2
<b>Total out of 33 (%)</b>	<b>18 (54%)</b>	<b>19 (58%)</b>	<b>23 (70%)</b>	<b>9 (27%)</b>	<b>16 (48%)</b>

#### SCERTS Learning Supports Checklist

Structures for active participation /5	4	4	3	1	3
Uses AAC <sup>a</sup> device to foster development /4	2	2	3	1	2
Uses visual/organisational support <sup>b</sup> /6	0	0	0	0	0
Modifies goals/activities/environment /10	7	8	9	3	5
<b>Total out of 25 (%)</b>	<b>13 (52%)</b>	<b>14 (56%)</b>	<b>15 (60%)</b>	<b>5 (20%)</b>	<b>10 (40%)</b>

Notes: <sup>a</sup>AAC: Augmentative and Alternative Communication; <sup>b</sup>visual support was not used as Leah is blind.



Table 7. *Vignettes describing two observed activities with Leah, including both the nature of her communicative bids and the strategies used by adults to support her.*

Ethnographic Data	SCERTS® checklists	
Narrative	Leah’s communication	Adult supports
<b>Vignette 1</b>		
<p><b>11am, school.</b> Staff tried to engage Leah during the hydrotherapy session by showing her a toy fish and asking her, “Who shall we squirt? We have [staff member] on this side (splashes in the water) and [staff member] on this side (splashes in the water)”. Leah did not indicate a choice, however. The staff still squirted the fish, but aimed it up in the air rather than at one of the staff members.</p> <p>Leah was given a second choice during the session – whether she wanted the ‘bubbles’ on in the corner of the pool. One staff member said, “smile if you want more bubbles”. Leah did not respond. The staff member tried to create the bubbles themselves, by moving their hands up and down in the water, but Leah showed no response to their bid. The bubbles were turned on anyway, with the staff considering that perhaps Leah was feeling tired.</p>		<p>Secures child’s attention before communication</p> <p>Uses non-verbal cues to support understanding</p> <p>Models appropriate play</p> <p>Offers choices</p> <p>Interprets problem behaviour as communicative and/or regulatory</p>

Vignette 2		
<p><b>5pm, home.</b> Leah demonstrated to staff that she was unhappy by frowning and saying “Ah” repetitively. Staff wondered whether Leah was uncomfortable in her chair. Her vocalisations gradually became louder and more persistent towards the end of the activity and she was therefore taken upstairs to the residential lounge where she was placed face down on a soft “wedge”, with her head over the edge.</p> <p>Staff explained that this position helped her to feel more comfortable and settled. Leah did seem somewhat calmer; she was making fewer vocalisations, although she was still frowning. A member of staff joined Leah and sat next to her on the floor. She started reading her a “Gruffalo” book, with buttons to make the noises of the characters and animals in the book. This was followed by another book, “Scary Sid”, which has a puppet combined with the story.</p> <p>Sid the puppet sometimes tried to ‘eat’ Leah’s fingers and this was extended into holding and jiggling Leah’s arms. Leah lifted up her head and smiled</p>	<p>Protests undesired actions or activities</p> <p>Soothes when comforted by partners</p> <p>Responds to partners attempts to re-engage in interaction or activity</p> <p>Re-engages in interaction or activity after recovery from extreme dysregulation</p> <p>Responds to sensory and social experiences with differentiated emotions</p> <p>Shares positive emotion using facial expression and vocalisations</p>	<p>Responds appropriately to child’s signals to foster a sense of communicative competence</p> <p>Modifies sensory properties of learning environment</p> <p>Arranges learning environment to enhance attention</p> <p>Infuses motivation materials and topics into activities</p> <p>Offers repeated learning opportunities</p> <p>Provides predictable sequence to an activity</p> <p>Uses appropriate proximity and nonverbal behaviour to encourage interaction</p>

when this happened. Throughout the reading session, the member of staff stroked Leah's back and held her hand.		Infuses motivation materials and topics into activities
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