GCU Glasgow Caledonian University

sense for deafblind people

# Joint attention in deafblind children:

## A multisensory path towards a shared sense of the world

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**Sense Joint Attention Project**
Extended Report

Sense Research

Joint Attention (JA) is a developmental milestone in human communication that typically appears around the first year of life. Communication in JA serves as a platform for cultural learning language acquisition and the intentional understanding of the internal world.

This project carried out a systematic investigation of JA in fourteen young children with dual/multi sensory impairment (DSI/MSI); its aim was to determine to what extent they use alternative sensory modalities to share attention and intentions about the world in the interactions with their parents. Results from the observations of child/parent interactions indicate that different levels of JA can be achieved through atypical sensory channels in order to fulfil typical communication functions. In fact, the study of JA in multisensory impaired children shows that JA is a multisensory phenomenon, something often overlooked in the literature of typical development.

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# 1. Extended summary

Joint Attention (JA) is a developmental milestone in human communication that typically appears around the first year of life. Through JA children show evidence of coordinated regulation of their own attention and the attention of others to communicate something about the world. Communication in JA serves as a platform for cultural learning, language acquisition and the intentional understanding of the internal world.

Most research in joint attention communication has focused on the visual modality. JA, however, is a multisensory experience where visual, auditory and tactual input is exchanged and integrated within the communication event. Children who are deprived of the typical visual and auditory input can still use other sensory modalities to communicate and share attention, intentions and the world.

The project presented here looks at the use of alternative sensory modalities in the early communication of deafblind children.

Fourteen young children with dual sensory impairment (DSI) were recruited from Scotland, England and Wales. All children were congenitally deafblind with a range of different aetiologies for their dual sensory impairment; all met the criteria of Sense definition of Deafblindness (DB) and had been assessed by professionals. This project presents results from both indirect and direct observations of communication behaviours in this sample. Direct observations consisted of samples of free play interactions between the child and his/her parent. Participants were provided with adapted toys and the parent was simply instructed to interact with her/his child using these toys. Results show that a third of the children in the sample do spontaneously engage in JA by using alternative sensory means; they call for their parent's attention, produce specific action or objects requests, engage in turn-taking by imitating actions performed on the object and share excitement or interest about objects through differentiated means. Communication behaviours of the remaining two thirds of the sample can be identified and coded as dyadic interactions (using alternative sensory means) that precede JA developmentally.

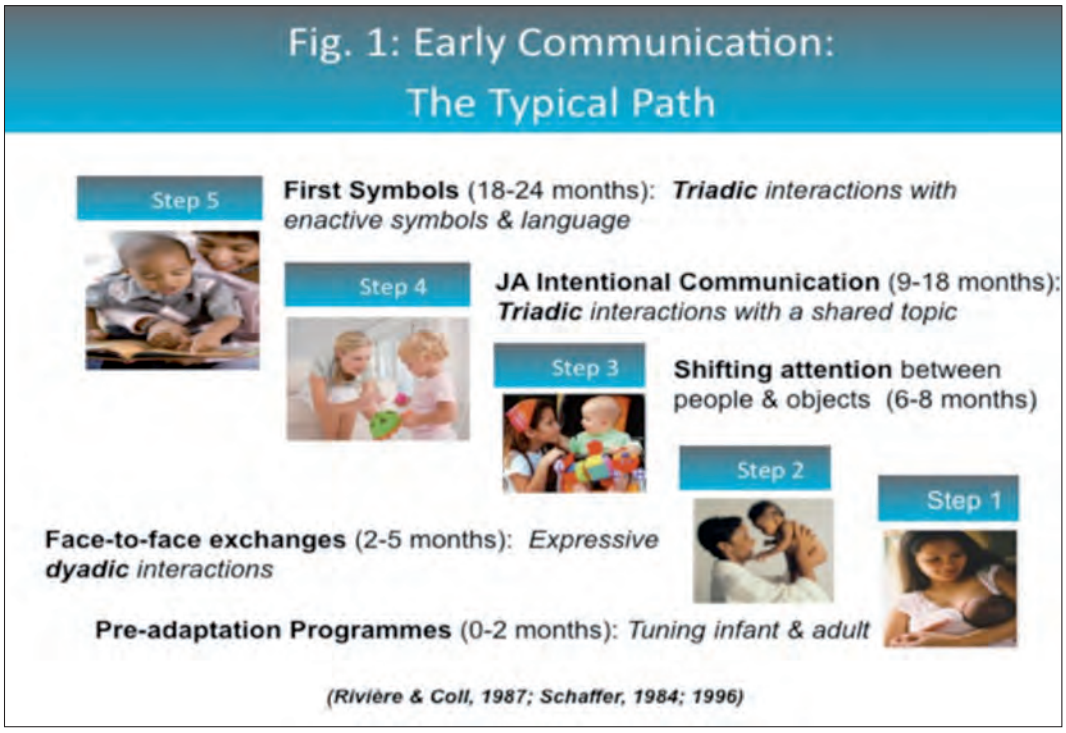
These findings indicate that different levels of JA can be achieved through atypical sensory channels in order to fulfil typical communication functions. Atypical sensory trajectories to JA can fulfil typical functionality in regulating other's attention, intentions and communicate about the world.

# 2. Looking at Deafblind Joint Attention from a developmental perspective

## The Typical Path to JA

Joint Attention is defined by coordinated sequences of actions, gestures, gaze and emotional expressions that include the self, the adult and the object into a shared focus of attention (see e.g., Franco & Butterworth, 1996; Carpenter, Nagell & Tomasello, 1998; Mundy & Newell, 2007; Grossman & Johnson, 2010).

The framework adopted for this investigation was a *developmental approach* where the path to Joint Attention (JA) and the development of symbolic communication is presented as a step by step (stage-like) trajectory in the communicative interactions between parent and child. Systematic changes in the regulation of attention, in the dyadic skills (such as mutual glance or eye-contact and turn taking), in the transition to triadic skills, gestures and symbols are well documented in the literature of infant communication when it follows a 'typical' trajectory (see Fig 1). (See e.g. Reddy, 2008; Reddy et al. 1997: Rivière & Coll, 1987; Rochat, 1999; 2009; Striano & Reid, 2009; Schaffer, 1984;1996)




In the developmental path to symbols, the stage of Joint Attention is a crucial step. The child's communication repertoire at this stage expands in a number of important domains as follows: (a) The regulation and understanding

of attention (his/her own and the attention of others). The child gains monitoring skills to direct, hold and shift the attentional focus of interest. (b) The *intentionality* of communication. The child can hold and express communication intentions through 'differentiated means' (such as intentional gestures pointing and coordinated attentional shifts, such as using gaze as a directional gesture too). (c) Objects are integrated in the communication exchange as referents –topics of interest (see e.g., Rivière & Coll, 1987).

As a precursor of linguistic communication, all these new skills are shown both at the *production* level (with the child initiating the interaction and using them) and the *comprehension* level (see e.g., Carpenter et al 1998; Behne et al, 2012). They also fulfil specific intentional communication functions such as requesting something (proto-imperative function) and, more importantly, sharing information (proto-declarative function) (Bates, Camaioni and Volterra, 1975; Franco & Butterworth, 1996). Recent experimental evidence in typical toddlers shows that these exchanges of information and the functions they fulfil are much more sophisticated than initially described with these two "proto-communicative" functions (see e.g., Franco, 2013; for a review see Harris & Lane, 2013).

With this new set of communication tools the child is equipped to learn culturally relevant information that would be unfeasible to discover based on direct exploration and observation of their environment alone. Children become active pupils in the interactions that follow the rules of a 'natural pedagogy' (Csibra & Gergely, 2009). For this reason early communication in JA serves as a *platform* in the child's development in a number of domains such as: (a) Cultural learning and cooperation (Tomasello, 1999; 2008); (b) language acquisition (Baldwin, 1995; Baldwin et al 1996) (c) socio-cognitive abilities such as the understanding of intentions and the internal world of others (i.e. in acquiring a "theory-of mind") (Tomasello, 1999; 2008; Tomasello et al, 2005) and (d) the acquisition of the higher order executive control of attention and action (Núñez, 2006; Núñez & Ingwersen, 2004; McGuigan & Núñez, 2006). Recent evidence on the selective brain responses to JA in infancy (Grossman & Johnson, 2010; Mundy & Newell, 2007) provides further support to the argument of JA as a platform for socio-cognitive development.

## JA & Atypical Development

The importance of JA in development is highlighted when we turn to look at atypical development. In a number of developmental disorders, problems with JA either precede and/or are related to crucial developmental impairments or

delays that characterise the disorders. The best documented example comes from research with children with Autism Spectrum Disorders (ASD). Altered JA in infancy serves as a "red flag" for early diagnosis of this condition and it is related to later core impairments in theory of mind and executive function in this group (see e.g., Charman et al., 2001).

Children with *single sensory impairments* show also delays in JA, although the literature in this area is much more limited (as compared to the ASD literature). Blind children delay in JA (Bingelow, 2003; Leekam & Wyver, 2005) has been described as an apparent "autistic-like" period during the end of infancy (Hobson & Bishop, 2003) that is later on overcome when language starts operating as the main means of communication in these children (Perez-Pereira & Comti-Ramsden, 1999). This pattern is likely to be related to the delay that blind children show in the acquisition of pragmatics and semantics (James & Stojanovik, 2006).

Deaf Children do not show impairments in the production of gestures (Goldin-Meadow & Mylander, 1984) and the standard frequency of JA episodes (Spencer et al, 2004) but deaf children of hearing (non-signing parents) do show a delay in symbolic JA (Prezdindowski et al., 1998). Children with hearing parents who do not have access to a shared symbolic system of communication at an early stage (known in the literature as "late signers") also show delays in theory of mind during the preschool and early school years. This delay, however, is not shown by deaf children who are "native signers" (usually children of deaf-signing parents) (see e.g. Woolfe, Want & Siegal, 2002; Peterson et al., 2005; Núñez, Donaldson & Byrne, 2010). This pattern of selective deaf-group delay in theory of mind has been recently shown also in toddlers (Meristo et al, 2012).

In sum, findings from the studies from single sensory impairments reveal that: (1) Being deprived from sensory input in either the visual or auditory modality has an effect in the development of referential communication; (2) having a linguistic or symbolic-sensory-adapted-system input in the early JA interactions can play a key role in the socio-cognitive developments for which JA is a precursor. (3) As compared with children with Autism, children with single sensory impairments show a delay, rather than a basic impairment, in JA. Much further research, however, is needed in these two populations in order to fully understand these connections.

## JA and deafblindness

If a single impairment either in the visual or the auditory modality has important consequences for the development of JA and the socio-cognitive skills that follow, no doubt the combined "dual" impairment in these two modalities must have a severe effect in the deafblind development. In the literature on defablind communication the "struggle" to symbolism is well documented (see e.g., Bruce, 2005; van Dijk, 1986). Most research in deafblind communication has taken place, however, in applied and educational settings (e.g., Bruce, 2005; Bruce & Vargas, 2007; Janssen et al 2002; 2003; Nelson van Dijk et al. 2002). Professionals and practitioners in deafblindness count with useful guides and materials that provide guidelines for the communication interactions with deafblind people and their assessment (e.g., Janssen & Roebroe, 2007; Nelson, van Dijk et al, 2002). These guides are based on developmental and basic research concepts. In their everyday practice, professional surely have come with their own tools based on the interactions with deafblind people.

There are also qualitative case studies with adults with solid theoretical foundations showing the use of tactile sensory means and gestures and imitation in the communication "in partnership" with deafblind adults (Hart, 2006 & 2010).

However so far there has been very little basic research that has specifically addressed JA in deafblind communication and, more importantly, carried out with young children from a developmental perspective. There are two exceptions to this. One is the research work carried out by Anne Nafstad in Norway who has been looking at the tactile joint attention in children from a semiotic perspective (Nafstad, 2008). Unfortunately, her work on this area has not been published yet so references here are secondary through the work of P. Hart (2010). Also in the Scandinavian context, Gunilla Preisler's work involves young children. She recorded 6 deafblind children interacting with their parents in real-life settings and found similar patterns than those of non-disabled children -in terms of the child's interest of sharing social games and sharing also experiences in JA with the carer (Preisler, 2006).

In conclusion, despite the practical knowledge in applied settings there has not been any systematic investigation completed on the development of JA of young children with deafblindness (DB) yet. This project was commissioned by Sense two years ago to study JA in young children with DB. By completing it, with the findings presented here we hope to have contributed to start filling this important gap in research.

# 3. Aims and research questions

This project carried out a systematic investigation of Joint Attention in young children who are deafblind, determining to what extent they use alternative sensory modalities to share attention and intentions about the world in the communication interactions with their parents.

This project aims to study the developmental path of deafblind Joint Attention, adopting a step-like approach as a reference to anchor the communication behaviours observed in young children who are deafblind.

More specifically the following research questions are addressed:

1. Do young deafblind children spontaneously engage in JA with their parents?
2. If so, what sensory modalities do they use?
3. Does JA meet the standard communication functions of early intentional communication?
4. Does the developmental path to deafblind JA follow a step-like trajectory?

In order to answer these questions, this project looked at parent/child interactions from direct observations but also gathered information on the participants' communication and sensory-motor skills through a set of parental reports, as described in the sections below.

# 4. Method

## Recruitment of Participants

Recruitment of the participants was carried out in various steps. First, professionals working with the families of children with DSI/MSI[1] (in special needs schools/units, family centres and charities and through other networks) were contacted to request their collaboration. They were asked to forward the call for participants and the information package to the families with deafblind children under the age of 7. The package included leaflets, letters addressed to the parents and a volunteer form. As indicated in the letters, participation was entirely voluntary; the contact details of the participants could only be obtained if facilitated by the families themselves. Seventeen families responded to our call. Two of these families had to cancel the appointments for health or other reasons and were not able to re-schedule. Fifteen families completed the first session but one of the children was eventually excluded in the final sample since he had a single (rather than dual) sensory impairment.

The final sample therefore included a total of **14 children** (4 girls and 10 boys). The ages of the participants ranged between 37 and 86 months, with a mean age of 39 months (4 years and 9 months).

All children in the sample were congenitally deafblind. The aetiology of their Dual sensory impairment (DSI) was mixed. This included 4 children with CHARGE syndrome, 3 with other known genetic conditions (altered Connexin 26; Hypomelanosis of Ito and Angelmans syndrome), 4 with possible/suspected genetic diagnosis or biological damage but not confirmed (e.g., Cockayne Syndrome or neural damage) and 3 children whose DSI had an unknown aetiology.

Children had DS impairment of different degrees (see Table 1). Half of the children in the sample had a profound or severe impairment in one of the two senses (either auditory or visual) but moderate to mild in the other sense.

[1]DSI/MSI Dual/Multi Sensory Impairment

| Table 1 | |
|---|---|
| **DS Impairment at different degrees:** | |
| **Visual I – Hearing I** | **No of participants** |
| P/S – P/S | 3 |
| M – S/P | 4 |
| S/P – M | 3 |
| M – M | 4 |
| **P = Profound S = Severe M = Moderate or Mild** | |

Three of our participants were profound or severely affected in both senses; the remaining 4 had a moderate to mild impairment in both sensory modalities.

Participants' associated disability ranged from none (except the developmental delay attributable to their DS impairment) to severe (see Table 2), although most children in the sample (12) were moderate or severely disabled.

| Table 2 | |
|---|---|
| **Associated disabilities at different degrees** | |
| **Level of disability** | **No of participants** |
| None | 1 |
| Mild | 1 |
| Moderate | 6 |
| Severe | 6 |

| Table 3 | |
|---|---|
| **Demographic info** | |
| **Parents degree** | **No of participants** |
| Standard | 1 |
| Higher | 2 |
| Graduate | 4 |
| Postgraduate | 7 |

## Assessments and procedure

Ethical approval was obtained in each of the three collaborating institutions following the standard regulations of each centre. The assessment sessions took place in various environments, at the family's convenience. Families who volunteered were invited to come to one of the three centres, where facilities for the observation were optimal; however, whenever it was not feasible or convenient for them to travel to the university centres, families were also given the choice of participating either in the school, family centre or their own homes. In all cases, the sessions took place in a quiet, DSI friendly room, following a standard protocol. On arrival, parents received further information about the project and the details of the session that would follow; then they were given the opportunity to ask any questions related to the study. Once any questions were addressed, they signed the consent form for participation and the assessment started.

The battery of assessment included a combination of direct observations and parental reports. The report materials were as follows:

1) A questionnaire including some basic information on the parents education, child's schooling, other siblings etc
2) A semi-structured interview on the child's communication.
3) The Communication Matrix completed online during the session
4) Some selected items of the INSITE (a battery to assess sensorimotor development in populations with sensory impairments and/or other disabilities) adapted by the team so they would be more intelligible for parents (trying to avoid technical terms or professional jargon and adding illustrative examples that parents could use as an anchor). These items included the assessment of cognitive development at the sensory-motor level (object permanence, means-end behaviour and understanding of causality).

The direct observations consisted of at least one non-structured "free-play" session of child/parent interaction that was video-taped for a minimum of 8 minutes. The observation situation included the child, the parent and a fixed set of novel objects/toys that were chosen in order to provide a range of sensory stimulation (visual, auditory, vibration, tactual etc). The toys were presented in a transparent plastic box and the participants were entirely free to choose which objects to use (or not use) for their interactions. Parents were given a simple instruction to "play/ interact with your child as you normally do, trying to make use of these objects (toys)".

For most participants, the assessment took place over two sessions. Session 1 included the recorded observational session, the questionnaire and the interview. The second session included the completion of the INSITE and the Communication Matrix by the parents assisted by the researchers. When a second session was not feasible, the completion of the communication Matrix was included in the first session and parents were given the INSITE assessment to fill in on their own time with our contact details for any questions or doubts they may have while completing the questions.

As scheduled, assessments of the participants started in Glasgow, then continued in London and were finally completed in Cardiff, between March and December 2012.

# 5. Results

## Assessment based on parental reports

### 1. Questionnaires: family context

Most children in the sample had at least 1 sibling and had their mother as the main carer; the ethnic background was mostly white British and most families used English as the main language at home although there were other ethnic backgrounds (Tamil, Jewish, other European) and linguistic contexts represented (4 children were developing in a bilingual environment, French/English for two of them, Portuguese/English and Tamil/English). All except two had a communication system (CS) introduced by professionals and all children had been seen by at least 3 different professionals.

The educational level of the families in our sample was high; almost 80 % of the parents who took part had a university degree (see Table 3).

### 2. Interviews: communication history and types of interaction

The interview was semi-structured, consisting of three sets of questions on three areas. The first set of questions aimed to collate some information about the child's disability (see participants details in previous section). The second set aimed to gather information about changes in parent/child communication from birth to the current level. The third section aimed to get some more specific information about dyadic and triadic forms of communication.

The interviews were transcribed and subjected to a qualitative, classical content analysis (Hsieh & Shanon, 2005). The analysis appears below. An outline of the topics that emerged after analysis of the transcriptions across the 14 participants appears in the Appendix on page 40.

## Interviews: content analysis

**Has your child had his/her dual sensory impairment since birth or was it acquired later due to illness?**

In most children the disability was present from birth, but clear diagnosis is a protracted process, so certainty comes usually much later (especially for hearing) if it is reached at all. C2 is an exception here. On a couple of occasions the diagnosis seems to have been too bleak, and children show more abilities than previously thought.

**Is your child entirely deaf and blind or do they have a little earing or sight?**
(See frequencies in Table 1)
What emerges here again is that there is uncertainty about the actual degree of impairment, and parents use their own observations as well as hospital results to understand their child's disability. Glasses/grommets are used to improve abilities, but children don't all respond well (sensory overload or annoyance with glasses). Other ways to capitalise on abilities is to work with outside agencies for support (listening work at school, vision consultant) and adapting the child's environment (lighting levels, understanding which sounds are upsetting). Children will also use their own adaptive strategies (adjusting position of head), and a lack of these (for example the inability to look down) can aggravate the effect of the impairment. Some details still need to be transcribed.

**Does your child have any other disabilities?**
The majority of the sample experiences other disabilities next to their deaf-blindness. Some of the disabilities may be caused by the deaf-blindness itself (some general developmental delay, problems with balance/walking). Associated disabilities include general developmental delay, learning difficulties, abnormality in muscle tone, and problems with feeding. These may stem from physiological, neurological or genetic causes (Charge syndrome, Angelman's, Connexin disorder).

**How has the communication you and your child share changed as they have grown?**
As far a possible- given that some children were incubated or attended hospital frequently - parents treated their child "normally," like they treated their siblings (only one child had adapted toys at an early age). They engaged in a lot of physical contact (feeding, rocking, hand play, soothing, cuddles & kisses, baby massage, bouncing), and used auditory and visual stimuli (singing, talking, lights). The awareness that their child was not developing normally grew when parents observed unresponsiveness in infancy or a delay in emotional responses and physical abilities. Because diagnosis is a lengthy process, parents were- particularly at the beginning - uncertain about what their child was experiencing, at times misinterpreting behaviour. Quote (L6): *"even though his problems were from birth they weren't diagnosed until he was a few months old so we just thought we had an extremely miserable baby".*

In addition to uncertainty about the child's impairment and possible future development, parents also face uncertainty about the meaning of their child's

expressions, needing to be interpretative of their children's behaviour, carefully reading of body language, facial expressions and noises. Some parents here express more confidence in their interpretations than others, as they perceive their children to be more expressive.
Diagnosis and outside intervention are reported to make a significant difference both to children's abilities to communicate and to parent's ability to perceive communication, helping them to better "read" their child. Quote (L4) *"A Sensory occupational therapist taught us to handle Katie differently. That Katie couldn't cope with light touch, that she liked firm pressure and when she was cuddled she liked to be held really firmly (…) and that changed everything for Katie. She started loving being held"*

Notwithstanding the help that professional agencies offer, building up communication is perceived as a slow and laborious process, and there are examples where not much change had been achieved, or not to the degree hoped for. This process of building communication is often guided by intuition and trial and error. Quote (C2) *"I don't know a lot of it's just instinctive, you do it and you don't really assess what you're doing but you're doing it"*. This instinctual response may translate into an awareness of what it is the child responds to and reacts to, for example responding to taps on the shoulder, waving arms in front of the child, and lead to adapted method of interactions (e.g. a use of music/ a firmer touch), or indeed a return to more basic forms of communication (e.g. returning from sign to body sign/ from pictures to objects of reference). Alongside this, parents become aware in how much their child's conceptual abilities or their temperament and personality may impact on their responses.

Singing, music and other rhythmic and vibration based activities remain important throughout development, and were mentioned by 5 parents. Depending on the child's abilities – parents then introduce communication systems like picture exchange system, makaton, signing and talking, though the child's attention or physical abilities might present obstacles.

2 children's parents reported that they respond to instructions. To request something, 6 of the children in the sample reach or point, although pointing may not have developed until the ages of 2 or 4 years. Other strategies to request include moving towards the object, bringing the object to mother, gesturing, vocalizing, using eye gaze, or performing anticipatory actions. Quote (L8) *"He does do things that make us know he wants something like if he wants to go out he will automatically grab his coat and put his shoes on".*

Choice is seen as important, and parents introduce this through co-presentation of objects, as some children are not able to acknowledge objects outside their field of vision. For some children communicating pleasure/displeasure has not moved much beyond smiling or crying. Other strategies include pulling hands away, turning their back to the toy, cover up their face, or pushing the toys away. Quote (G2): *"He claps hands when very excited so you know to continue whatever you're doing."*

In terms of perceiving people, parents note the progress their children make. While some children clearly focused on the parents' foreheads or expressions or smiled back at them, some of the children were locked in their own worlds in infancy, and eye contact was not always present. This is actively fostered by parents, as is joint attention through hand under hand exploration. With development children in the sample became more aware of people and people's reactions, were more ready to approach, learned to distinguish between familiar and unfamiliar people (although the verbal labels given may not always reflect this) and show an awareness of individual psychological characteristics. Quote (G3) *"So if it's someone familiar he will sit up and be making noises in their face. His teacher of the deaf came for a home and as soon as he saw her he was right in her face making noises trying to communicate to her."* One mother explicitly commented on turn taking, which her child developed at age 4.

**When you communicate with your child, do you spend a lot of time one on one playing and interacting? (Give an example, e.g., tinkling, imitating their actions etc). Does play/communication involve toys/objects as well?**
There is an indication that 1-on-1 play precedes play with objects, in that some children in the sample are more able to play 1-on-1 than with objects, and even those children who play with objects have developmentally preferred 1-on-1 play before progressing to objects, or revert to 1-on-1 play once they are bored. The exception to this are children with autistic-like behaviours who prefer completely solitary play or mouthing objects.

In terms of play without objects, physical contact is important, for example through rough and tumble play, tickling or cuddles. The importance of the body is also highlighted by C1's copying of facial expression or the use of fingers for counting games.

With regards to play with toys, some children in the sample are able to play by themselves, with conventional toys, adapted toys or ipads. How toys

are introduced seems to be important, in that they need to be introduced repeatedly over a period of time, and play with toys may need to involve a lot of adult time in order to calibrate play to child attentional abilities. The involvement of school in teaching how to play is acknowledged. If care is taken, progress in play may be observed (L6's mum comments on a progression from ignoring toys to whacking to manipulating toys). Reciprocal, communicative play with toys is described as more difficult than solitary object play (G1 for example is only able to throw a ball back and forth) and needs more parental attention and intervention, for example by performing an action jointly or getting the child to imitate.

Parents are aware of the use toys for education, and while L6 doesn't like educational toys, parents of other children use toys specifically to teach certain abilities like using PECs, naming drawn objects, or focusing on the child's understanding of cause and effect. Parents also use toys to introduce choice. Other important play behaviours include children's ability to request more and to initiate, particular for familiar activities like singing together or drawing.

Once again, the importance of music, rhythm and/or vibration in particular is evident both in 1-on-1 play and in play involving objects, for example through singing nursery rhymes, listening to CDs, joint book reading or the use of resonance boards. Other attractive things that draw on different sensory modalities include toys with lights or joint cooking. For very disabled children like C2, the mother brings the toy in physical contact with the child, letting her daughter feel texture and vibration.

**Do you communicate with your child *about* other people or objects, toys?**
Not all children have *new people* introduced to them, and the process of getting to know new people can be slow. Children may initially refuse to interact and only slowly build up contact, preferring interactions with a few close people, like key workers or close relatives, depending on whether they like the attributes of the person (tone of voice/style of play) or not. Explicit approach behaviours to new people were described by parents of G1, who uses smell as a process of familiarization, whereas C2 was clearly getting excited by hearing human voices. Once a person has been accepted, children's communication is described as affectionate (L4), culminating in the ability to form friendships (L1).

Parental strategies to introduce new people centre around talking about the people/using pictures to communicate about people, teaching hallo and good

bye waves, with G1's parents also teaching new people how to approach their child. School is mentioned as a positive influence, in terms of learning through social stories, learning to name people and to foster friendships (L1). However, when the child is easily overwhelmed by the presence of unknown people, parents might be helping the child in *reducing* social contact in unpredictable settings.

Communication about objects/toys: For some children, it seems to be important to have time to explore objects independently, and it is crucial that they are not rushed with this exploration or with an introduction of a new toy. With regards to joint object exploration, parents may demonstrate the use of an object through hand over hand techniques. Communicating about an object is done through makaton and verbal description, even if it is uncertain if the child understands words. L6's mother draws on songs to introduce her child to tactile play, an idea that was introduced to her by the school. Intervention from care teams is also acknowledged.

**Have you had any communication systems introduced to you by professionals?**

The parents of 2 children stated that they had not been introduced to any communication systems. Parents of 9 children use sign, makaton or body sign, while 7 use PEC or objects of reference. These systems have usually been introduced by school or through other agencies such as Sense. Concerning these agencies, one mother mentioned the importance of the sensitivity of the outside caregiver.

Parent-identified barriers to the use of communication systems include a lack of interest or motivation of the child or the task being too difficult for the child, for example requiring skills like eye contact that was not present. In these instances parents need to actively work on the underlying problems first. Barriers on the part of the parent include finding the system too hard or unnatural, and in one case the desire for the child to use verbal language rather than sign. Being sensitive to the child's responses, maintaining routine, and giving time are seen as important factors in the development of communication.

**How does your child initiate communication with you?**

Apart from initiating interaction during play, children initiate interactions to satisfy physical needs or express discomfort, displeasure or the desire for preferred games or repetition. Initiation behaviours include physical

interactions with a sibling or the actual searching out of parents in likely locations, which may depend on the physical ability to move around. Proximal behaviours include for example G2 giving his feet to parents to turn him around.

**Is there anything else you would like to say?**

Parents highlighted the tensions between outside intervention and their own experience. One mother commented on the fact that she at times thought that her child could hear better than the doctors had told her, and one mother expressed disappointment at a perceived lack of intervention and support at a critical moment, saying that she had felt that her son should have been pushed more. On the contrary, another mother praised the support she got for teaching her to be patient and a fourth mother shared her joy at unexpected progress of the child, perhaps indicating an important role of parental expectations.

## 3. INSITE: Sensory-motor assessment

Table 4 shows the mean score of our sample in each of the sensory-motor skills assessed by the INSITE. The mean scores indicate that, despite a range of variation, children in our sample are within the developmental cognitive stage where intentional communication and joint attention develops in the typical trajectory.

**Table 4**

**Sensorimotor assessment INSITE**

| Skills | Mean total score |
|---|---|
| Object Permanence | 10 (max 15) |
| Object Exploration & Basic Schemas | 5.7 (max 11) |
| Means-End behaviour | 6.4 (max 13) |
| Causality | 4.8 (max 8) |

## 4. Communication matrix

The communication matrix provides individual profiles for each child in a number of domains of communication (e.g., requests or expressive skills) (Rowland, 2009; 2011). The matrix provides a descriptive assessment that places the child's communication at different areas as characteristic of a certain level (or levels). Levels range from I to VII, from very basic forms

of communication to the use of language. Table 4 shows the distribution of participants across the matrix levels of communication. Levels I to III are characteristic of dyadic interactions in our developmental framework; intentional communication including objects as referents starts at levels III – IV (the JA level). As Table 4 shows, the communication behaviours of half the sample lie under pre-referential levels (levels I to III) and the other half under triadic levels (levels IV-VII). Only one child in the sample shows the most basic level of communication and only one shows language at the symbolic level, according to the information gathered with this tool.

| **Table 5** | |
|---|---|
| **Max Communication Matrix level** | **No of participants** |
| Level I-II | 1 |
| Level II-III | 5 |
| Level III-IV | 1 |
| Level IV-V | 3 |
| Level V-VI | 3 |
| Level VI-VII | 1 |
| **Level of interaction skills** | **No of participants** |
| Dyadic | 4 |
| Transition | 2 |
| Triadic | 8 |

## Observational data

The minimum time of recording aimed was 10 minutes but recordings were adjusted to the child's/parent's needs and stopped with any signs of fatigue. The observation sessions lasted between 8.26 min. and 20.15 min. For all participants except three, the recordings are above 10 mins. in duration.

Recordings of each participant's communication behaviour were subjected to a descriptive analysis from a developmental framework with two main aims:

*(1) To Identify dyadic & triadic behaviours through any sensory modality used*

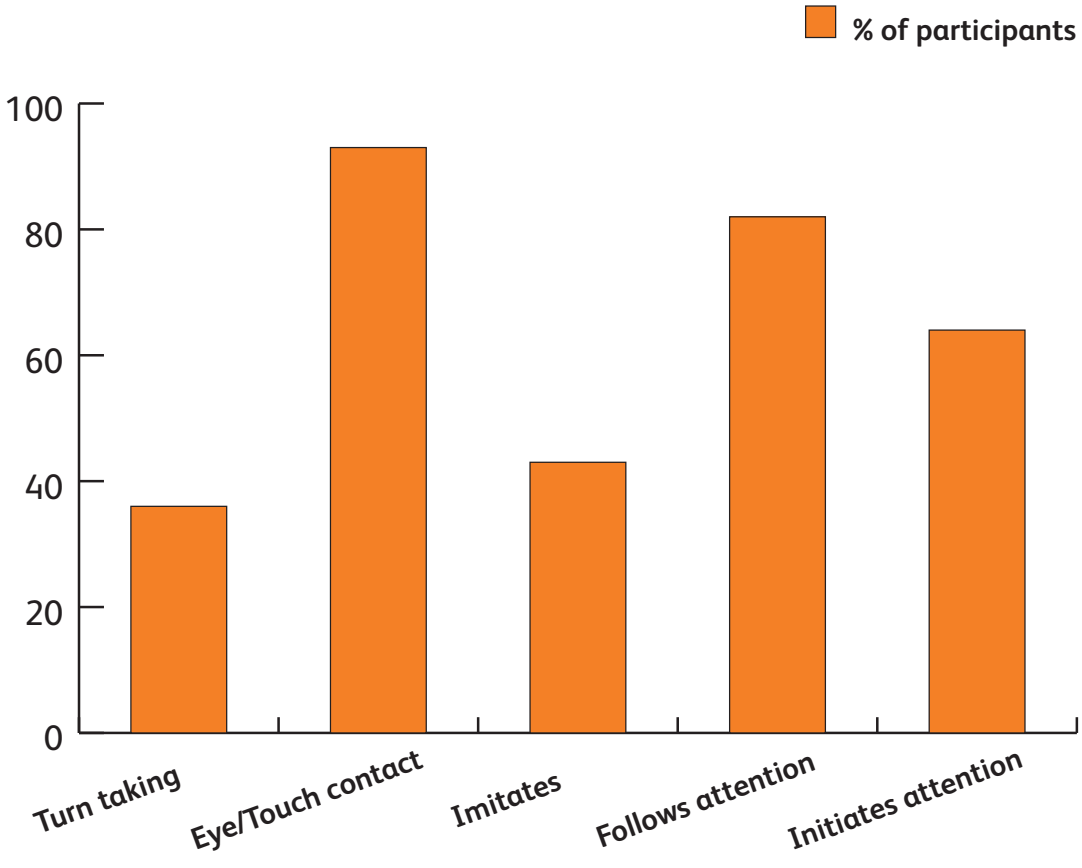
*(2) To Identify the 'communication' stage for each individual irrespective of her age, disability or sensory modality used*

## Frequency of Dyadic & Triadic Skills

In an initial screening analysis, recordings were watched independently by two researchers who noted the child's behaviour during the interaction on a list of 5 dyadic and 5 triadic communication skills observed in the interactions. The agreement of the initial checklist was high (over 88 % in all cases) and disagreements were resolved by discussion. Figures 2 & 3 show the distribution of the dyadic and triadic communication skills. Most children showed eye or touch contact (93 % ) and were able to follow an attention bid by the parent (82 % ). Around half of the children also initiated at least an attention bid (64 % ) and imitated the parent (43 % )[2]. Turn-taking was noted in 36 % of the participants (see Fig 2).

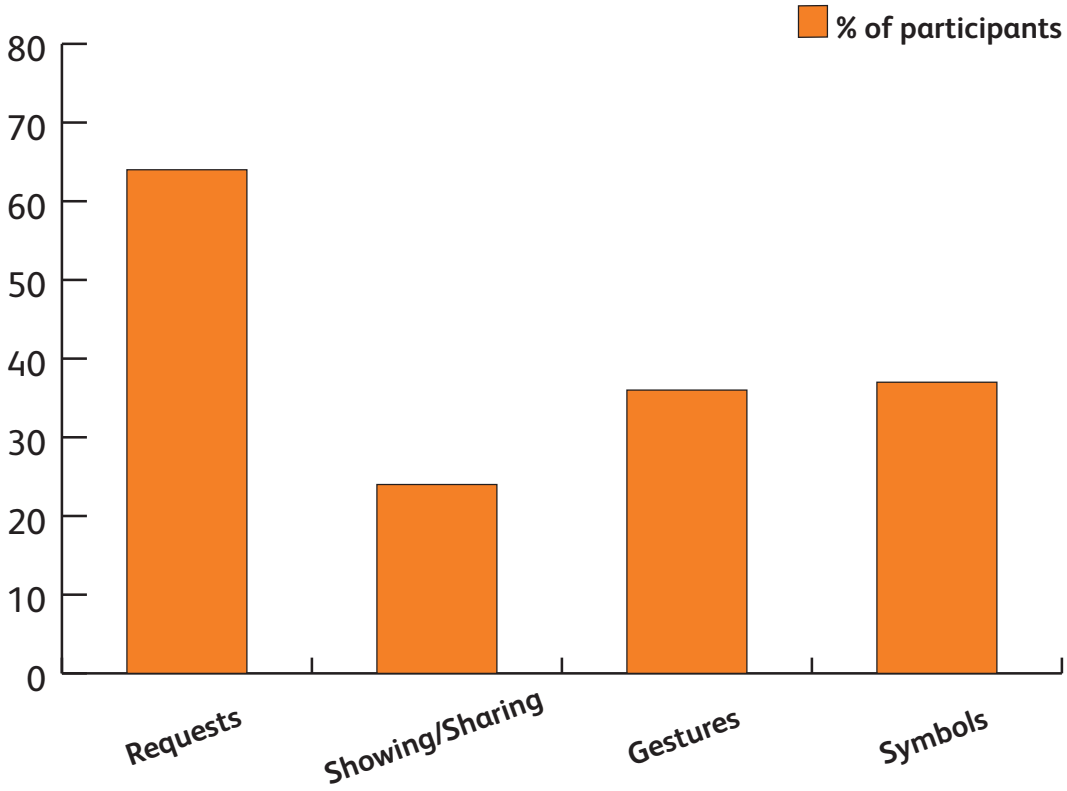
Requests were observed in 64 % of the participants; showing/sharing an object was shown by 24 % of the participants. Pointing was shown only by 2 participants; other gestures (such as e.g. holding a hand to direct the parent towards something) were more frequent with 36 % of the children showing them. 'Symbols' (e.g., words, signs for more etc) were shown by 37 % of the children (see Fig 3)

**Figure 2:**




[2] Imitation here includes emotional expressions, vocalizations, actions or movements.

**Figure 3:**




## Identifying Joint Attention across different sensory modalities

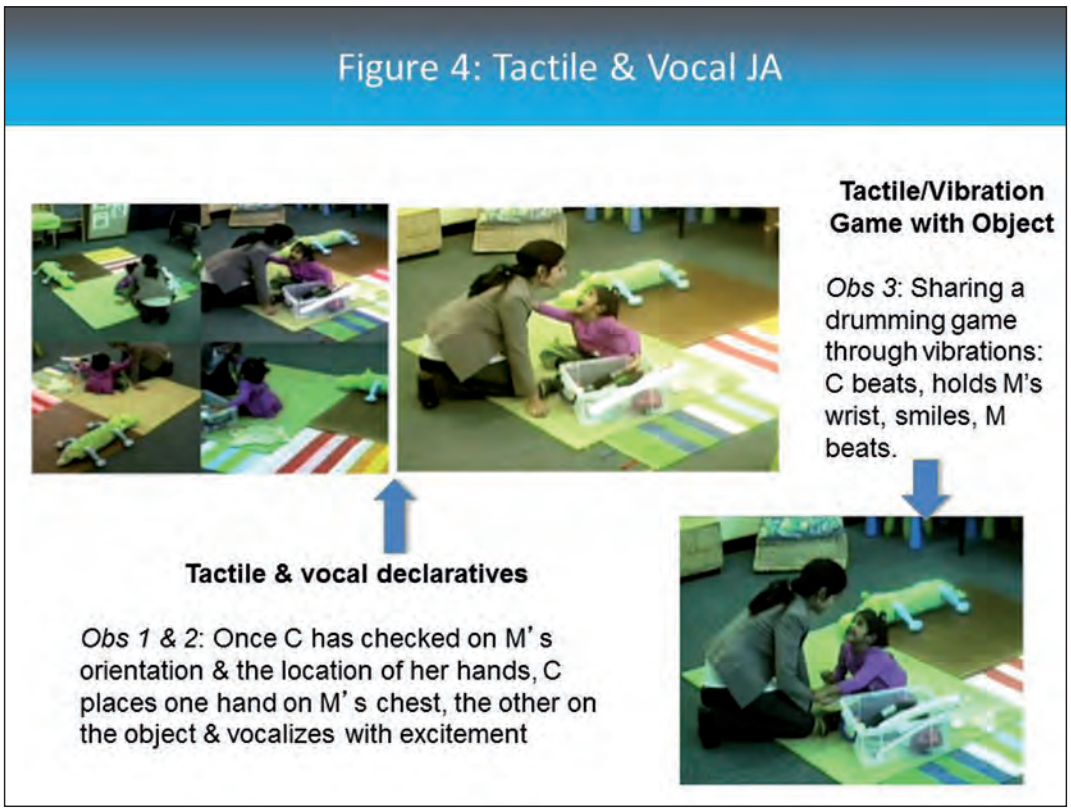
After the initial checklist screening, recordings were observed in search of specific episodes of Joint Attention as case studies. Identified cases were subjected to a detailed analysis of the sequence, noting descriptive observations in the sensory modality (or modalities) used, the specific communication function fulfilled and the sequence they followed.

Joint Attention episodes appeared clearly in a third of the recordings. The examples below illustrate how JA is established across various sensory modalities, depending on the nature of the DSI of the participant.

## Tactile and vocal joint attention (Fig 4).

The participant in this example is a 3-yr-old girl, with Profound Visual and Hearing Impairment. At the time of the recording she had had bilateral cochlear implants for 6 months but was not responding to sound yet. The cause of her DSI Cause mentioned by the parents was Genetic (altered Connexin 26). She had no known associated disability.

This participant was seen in one of the university centres *(The Toddler and Preschooler Lab)* equipped with 4 cameras that can be operated in a separate edition room during the recording.




The left-hand picture of Fig. 4 shows an illustration of the initial episode of JA, initiated by the child when she is placed next to the box of toys by the mother, seated in front of the girl. The child (C) notices an object in the box next to her by touching it and immediately checks for the mother's (M) orientation and the location of her hands by following the line of M's arms. Once the C has *tactually* checked that she has her mother's attention, she places her right hand on the mother's chest while holding the object of interest in her left hand; directly orientated towards her mother's face, produces an excited pleasurable vocalization ("ahhh") and smiles. The mother replies by talking and smiling back to the child (who can feel her voice through the hand placed on the M's chest). The C further explores the object; in the same position, vocalizes again and then brings M's hand to touch the object together.

This sequence presents all the elements of JA at the "production" level as follows:

- Initiation of attention bid: The child initiates the attention bid
- Attentional *tactual* (rather than visual) shifts between the mother's hands and the object (tactually)
- Production of a differentiated gesture while co-touching the object and the M's hand (tactile and vocal gesture)
- Gesture with a differentiated declarative function - sharing with M the excitement of finding an object that C enjoys and eventually showing it to M.

The example at the right-hand-side panel of Fig. 4, shows another example of JA by this child. Initially the mother starts the interaction introducing a new object (a little drum) by handing it to C and beating it slightly. C holds the object and imitates the two beats. While holding the drum, C grabs M's wrist and waits for M to take her turn in the game. M's beats twice and C smiles and vocalizes expressing pleasure.

These two instances quite 'literally' show the standard triadic interaction; the triad of the self, the other and the object can actually be 'seen' linked together through the tactual establishment of JA.

### Tactile & visual Joint Attention

The participant in Fig. 5 is a 3-yr-old girl with a Moderate VI (delay in visual maturation, possible cerebral visual impairment; strabismus) and Profound HI. The cause of her DSI is unknown but has a multiple associated or suspected aetiology (e.g. Microcephalia, possible Cockayne syndrome). This recording was taken in the London Centre (Middlesex Babylab) where there were two remote-operated cameras installed.

Fig. 5 illustrates two further examples of JA combining two sensory different modalities, tactual and visual in this case. The pictures in the left-hand side illustrate examples of a 'showing' JA game initiated by C and repeated with almost every object in the box. M & C are facing each other. The box with objects is to the left of C. C picks up an Object (e.g. the drum), turns to the M, shows it to her and they hold it together. C throws it to the floor and looks back to M before starting the same sequence with another object in the box (e.g., a ball).

In this example the differentiated gesture is showing/giving and the communication function is declarative (sharing the object with M).
The picture on the right-hand side of Fig. 5 shows another example of Visual and tactual JA, this time initiated by the mother while the child is touching an object inserted in a water-filled pad (see description of Observation).

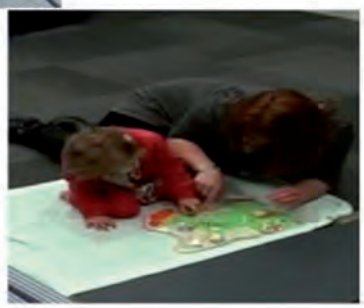
## Fig 5: Tactile & Visual JA

**Tactile & visual sharing**

*Obs 6*: C is touching O in a water-filled pad. M places her index finger on the same O and looks at C. C looks at M & they touch O together

**Tactile & Visual Giving & Sharing**

*Obs 4 & 5*: C takes O out of the box, shows it to M, then they touch it together and C places it on the floor. C looks back.



### Visual, auditory and symbolic JA

The participant in the examples shown in Fig. 6 is a 6-year-old girl, with Moderate but complex VI (No central vision, left eye: 1/60; right eye: 6/18; cataracts left & right) and a Severe to moderate HI that is partially corrected with hearing aids. The cause of her DSI is genetic (Hypomelanosis of Ito). She has also a moderate physical and intellectual disability associated (low muscle tone, learning difficulties). The recording took place in a quiet room in one of the special schools in London.

## Fig. 6: Visual, Auditory & Symbolic JA

**Sign**

*Obs 12*: M asks whetehr C wants 1 or 2 balls. C signs "two" on here forehead

**Pointing & Request**

*Obs 10*: M & C are playing a turn-taking game of rolling a ball & and shake it. The ball rolls away and C points while uttering 'there'. *Obs 11:* C requests a second ball that M took out of the box by extending her hand with an open palm and uttering a verbal request.

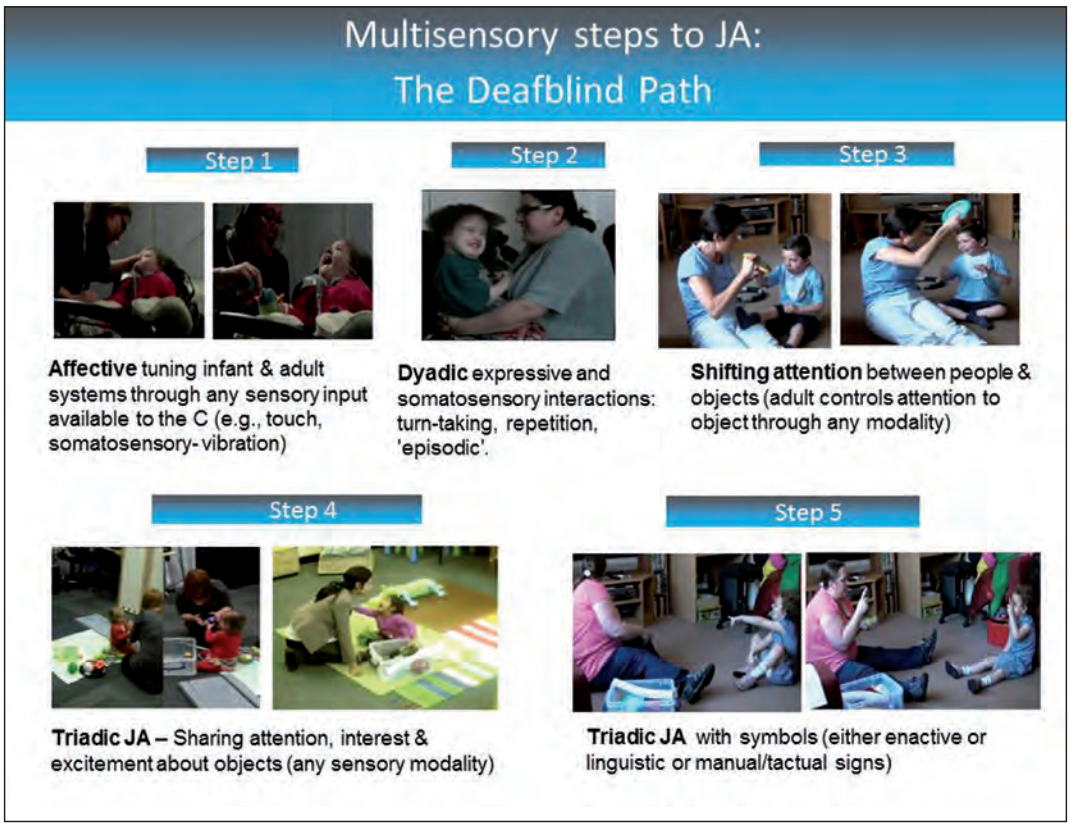
The JA observations in the interactions of this girl with her mother are the most elaborate, flexible and rich in the sample. She uses distal gestures (pointing and hand extension requests), manual signs, enactive symbols, rudimentary language and complex imitation. (See noted observations in Fig 6 for examples).

At different levels of complexity, all these three cases show JA by using alternative multisensory means (from the simple showing and sharing to the symbolic exchanges). In all instances these children call for their parent's attention, produce specific actions or objects requests and/or sharing, engage in turn-taking by imitating actions performed on the object and share excitement or interest about the objects they communicate about.

## Steps towards and beyond JA

Even if only a third of our sample showed clear examples of JA sequences, the observations noted for the rest of the participants allowed us to place them developmentally in one of the 5 standard steps in the developmental trajectory to symbolic JA. Observations across the 14 participants provided examples of multisensory communication in every step.

Figure 7 illustrates examples of each of the levels that were observed in our sample. Initial emotional contagion and 'tuning-up' of M/C communication was shown through touch and apparently synchronized voice to the child's breathing. Examples of dyadic expressive exchanges were identified through turn-taking in somato-sensory games and rhythmic movements (step 2). Some children also showed the characteristic 'transitional' stage where they indicate interest for objects but are not able yet to incorporate them into the communication event (step 3). JA is observed at different levels through various combinations of sensory means (as described in the section above). Finally, JA is also identified in symbolic exchanges that bring the interaction beyond the immediate, concrete present context.




## Coding Categories: Dyadic and Triadic communication skills leading to and defining JA

After the systematic, descriptive observations of the videos, we worked on a system of categories that could account for the dyadic and triadic skills that precede, are involved in, or follow communication in JA developmentally. A total of 13 global categories were identified and defined (see list below). Each of these categories includes a number of layers indicating details on, e.g., the sensory modality in which the communication skill is shown or the specific types of behavioural responses that indicate that skill.

All participants have been coded using this system of categories through ELAN (an annotation software programme that allows coding the videos frame by frame in multiple layers) (http://tla.mpi.nl/tools/tla-tools/elan/). Both the frequencies of the behaviours and the timing of occurrence are registered. These results are still pending on inter-rating reliability –which will be completed by January 2014.

The list of the 13 supra-ordinate categories is as follows:

1. Orientation to external event
2. Responds to attention bid
3. Follows attention bid
4. Initiates attention bid
5. Eye/Touch contact

6. Vocal Responses
7. Gestures
8. Symbols
9. Imitation
10. Turn-taking
11. Joint Object Exploration
12. Joint action, no object
13. Solitary object exploration.

# **6.** Main Findings. Multisensory Joint Attention: the deafblind path

Taken together the findings of this project can be summarised as follows:

1. The project includes a heterogeneous, inclusive sample that appears to be a fair representation of the young deafblind population in terms of the variability of aetiologies, level of combined Dual Sensory impairment and the level of associated disability. Despite the heterogeneity and variability characteristic of this population, the findings indicate that common threads can be identified in the nature and developmental features of the communication behaviour of young children with DSI that lead to JA.

2. Parental reports from the interviews indicate that the process of building communication with their children is arduous and they point out the difficulty of introducing new objects and/or people in the interactions with their children. In the observation situation our participants were faced with the 'challenge' of introducing new toys and communicating about them with their children. Even in this demanding situation, our participants demonstrated communication skills that can be identified as either developmental precursors of JA or JA at different levels.

3. Descriptive analysis of the observational data show that children with DSI do engage spontaneously in JA with their parents. Examples of Joint Attention are not frequent but can be identified through specific core skills (e.g. attention shifting and gestures) and through the communication function that they fulfil.

4. Joint Attention instances in DSI can be defined across different sensory modalities and in all cases *integrate* two or more sensory sources in the communication event. This can include tactual and vocal, visual and auditory, tactual or visual.

5. Tactile instances of JA allow us to quite literally 'see' the triad of the self, the other and the object linked together through the tactile modality in the triadic interaction.

6. The identified examples of JA through alternative sensory means reveal the standard characteristics shown in the typical trajectory. First, they show

different levels of complexity (from the simple showing and sharing to the symbolic exchanges). Secondly, and irrespective of their complexity, children in these observed cases call for their parent's attention, produce specific actions and/or object requests and/or object sharing, engage in turn-taking by imitating actions performed on the object and share excitement or interest about the objects they communicate about.

7. Not all children in our sample show JA but their communication behaviours can be identified as characteristic of one of the developmental stages that precede and lead to JA.

8. The deafblind path to JA and symbolic communication can be traced through the observational data gathered in this sample, having representative behaviours at all the stages in the trajectory.

# **7.** General conclusion: Atypical multisensory developmental trajectory that can fulfil typical functionality

Different developmental levels in JA can be achieved through *atypical* sensory channels to fulfill *typical* communication functions. Almost 'paradoxically' the study of JA in deafblind children shows that JA is a multisensory experience, something 'typically' overlooked in the literature on typical development. This highlights that the understanding of communication in children who are deafblind is not only relevant for potentially assisting practice and intervention in this population but also for understanding developmental processes themselves.

# 8. Outcomes

### Dissemination:

As proposed, the findings of this project were presented at two international conferences; the APS (Association for Psychological Science) Annual Convention in May 2013, and the 8th European conference of DeafBlind International in August, 2013. The choice of these two conferences was to target two main research forums where the findings of this project can make a significant contribution, namely psychological/developmental research and the applied educational and professional deafblind contexts. In addition to these papers, initial results were presented at the *British Psychological Society, Developmental Section*, Conference in Glasgow, September 2012.

Two further presentations were given by invitation in 2012 at:

1. The Parent and Infant clinic (London, June 2012) where the audience combined senior therapists and therapists in training to work with young children and parents.
2. Deafblind conference in Cardiff and Birmingham November/December 2012. The audience consisted mainly of professionals working on deafblindness in the UK.

A short summary of the project was published in the Newsletter of the Mary Kitzinger Trust this year and another invited presentation will be given in the research meeting of this Trust in May 2014.

As agreed, two papers are under preparation for two international Journals with high impact and with open access, as follows:
*Psychological Science* (paper co-authored by F. Franco & Susan Leekam) and the *Journal of Visual Impairment and Blindness* (paper co-authored by F. Franco, Susan Leekam and Susan Bruce).

The dissemination of the findings so far has also been fruitful in initiating potential international collaborations and establishing a research network. These added outcomes could take this research much further than its original aims and may generate international funding for future projects. Currently, we are in touch with S. Bruce (Boston College), the team of M. Janssen in Groningen (The Netherlands) and A. Naftstad and colleagues in Norway.

# 9. Acknowledgements

Throughout these two years many people have contributed to make this project possible. The people listed below are thankfully acknowledged for their contribution to many different aspects of the project:

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Susan Bruce (Boston College)

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Anna McGee and Steve Rose

### Sense Scotland:

Paul Hart and Rachael Tonge

### Schools & Family Centres:

- Hazelwood School (Glasgow): Jane Eyre
- Linden Lodge School (London): Mia Dodsworth
- Woodside Family Centre: Helen Potter

### Research Assistants:

- Jess Butcher & Birgit Schroeter (Toddler & Prechooler Lab, GCU)
- Tatiana Sobolewska (BabyLab, Middlesex U.)
- Kate Ellis (School of Psychology, Cardiff University)

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All practitioners and professionals who helped with the recruitment.

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# **10.** Final notes:

Details on the progress of the project across the different stages can be seen in the presentations and minutes of the Steering Group meetings. If further details on this respect are required, the PI is most willing to provide them.

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# Appendix

## Communication changes as the child has grown

- Late diagnosis: Frequently the child was not diagnosed at birth. The parents treated the baby normally but faced unresponsiveness on the part of their child and disconcert/uncertainty on their side
- Uncertainty: They expressed uncertainty about how to read the child's expressions, - although there was variability in the level of confidence expressed
- External intervention as a turning point: Parents pointed out that diagnosis and external intervention was a significant turning point in the communication with their child.
- Communication as arduous: Building up communication was perceived as a slow and laborious process guided by intuition and trial/error.
- Progress in communication was described in most cases. Parental intense fostering of abilities such as eye/touch contact & hand under hand exploration were mentioned. Parents noted that as children get older they become more aware of people & distinguish un/ familiar people.

## One to one interaction vs interaction with objects

- Parents indicated a preference for one to one interaction before play with objects in most cases
- In communication without objects physical contact and touch were highlighted as important.
- Communication/play with objects is described as more demanding for parents – may need to introduce an object over a period of time, calibrating the child's attention by e.g. performing action jointly or use of imitation.
- Both for one-to-one and for object communication music, rhythm & vibration are highlighted as important.
- Many children do not have new people introduced to them.
- Building new interactions is described as slow and difficult. Strategies mentioned by parents for this purpose are talking/ using pictures, teaching hello & wave bye.
- Strategies for communication about objects – parents sometimes let the child explore a new object before introducing it to him/her. Use of Makaton and verbal description; Use of objects hand-over-hand.

## Initiation of communication by the child

- Besides play, children initiate interactions to satisfy their physical needs and express discomfort
- Strategies mentioned vary from (e.g.) physically searching for the a parent in likely location, to (e.g.) offering a foot to be moved around

## Communication systems (CS) introduced by professionals

- Most children except 2 have had a CS introduced (e.g., Makaton, objects of reference, signs)
- Parents mentioned a number of barriers to using these CSs from feeling very unnatural to the child to not being adequate in their attentional abilities.

# About Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist servicesto all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single-sensory impairment with additional needs.

## Sense Research Team

Sense carries out robust, pioneering research that is directly relevant to people with dual sensory impairment. We keep abreast of the latest developments world-wide and use this knowledge to inform our practice.

Sense is uniquely positioned to respond to the needs of deafblind people across the whole of the lifespan. We are often the first point of contact for information about up-to-date research into the experiences of deafblind people, their families and their carers.

Our research strategy is also intended to alert the wider research community to the need for research related to deafblindness.

### To find out more

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