Exploring Language and Communication in an Individual with Congenital Deafblindness:
A Case Study

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July 2009

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EXECUTIVE SUMMARY

Introduction

The combined hearing and visual impairments associated with congenital deafblindness severely diminish access to information from the environment and impede opportunities for interaction and development of symbolic language. Congenital deafblindness involves the impairment of both vision and hearing to such an extent that an individual cannot function as someone who is deaf or as someone who is blind. The term *congenital deafblindness* covers a spectrum of combinations of varying degrees of vision and hearing loss. A total absence of vision and hearing lies at one end, while at the other end, residual vision or hearing, or some residual facility in both senses, is available. The degree of impairment varies within this population, which precludes generalising as regards successful remediation strategies. Concomitant physical or cognitive impairments will bring further challenges. People with congenital deafblindness who are able to use their residual sight or residual hearing are at a relative advantage, availing of communicative options that make use of the residual sense. Nonetheless, individuals who present with impairments within the spectrum of combined hearing and vision loss are at a great disadvantage when developing communication.

Educational strategies for promoting communication and language in this population generally advocate an individualised approach (see McInnes and Treffrey, 1982; Van Dijk, 1986; Nafstad and Rødbroe, 1999; Chen and Downing, 2006). Many different strategies may be utilised when supporting language acquisition. Such methods involve the use of sign systems and tangible objects of references. Examples of sign systems are formal sign language, adaptive signs and natural gestures. Tangible objects of reference are those that are used to refer to other objects, people, places and activities. They can be concrete representations, for example a spoon used to refer to dinner time, or abstract representations, for example an arbitrary piece of fabric that is used to refer to a day of the week.

Stereotypic behaviours are commonly observed in individuals who are deafblind. Idiosyncratic or stereotypic behaviours may appear unconstructive but could prove beneficial to developing communication. A type of echolalia (using signs instead of speech) and imitation rituals are sometimes exhibited by individuals who are deafblind, and may be significant in efforts to communicate for this population.

Methodology

This paper focuses on the emerging language capabilities of Amy, a young girl who is congenitally deafblind, with the aim of identifying educational strategies that may support her potential for language. Over almost a year, a range of activities were videotaped at home and at school. The study was observational in nature and no intervention occurred. The video clips collected were documented and those containing some type of communicative exchange were transcribed using a modified version of Jefferson's (2004, pp. 24-31) transcription system, a method adapted from the area of conversation analysis. The transcriptions were examined for communicative behaviours such as gestures, sign systems and objects of reference and the functions of such behaviours were identified. The clips were divided into

three time periods (Time 1-3) and analysed. Use of a repeated signed routine was examined with respect to its possible functions.

Findings

The developing use of sign language, especially the use of formal sign language, is evident in the data. Use of a repetitive routine which was reinforced through imitative sequences by Amy's family and teacher was important to her communication efforts. Over the course of the study, the repetitive routine increased in terms of both sequence length and vocabulary, with additional formal signs featuring within the routine. Three word sentences also appeared, suggesting grammar development. Formal sign language was the most frequent type of communicative act utilised, with use of abstract objects of reference (miniature forms or parts of objects) also evident. Natural gestures or bodily perceived gestures, which are individually motivated signs, and involve a re-enactment of an experience with the body, increased over the study period. These individualised gestures were implemented within the repetitive routine as well as in other conversational settings.

Conclusions

The level of communication and language-related abilities of a girl with congenital deafblindness are outlined in this paper. Suggestions are made concerning ways in which language potential might be recognised and acted upon. Particular attention was directed at emerging formal sign and routine sequences; repetitive routines may appear unconstructive but when channelled (for example, imitated by a communication partner), they may aid further language development. This and other suggested strategies reflect the need for an individualised approach to developing communication and the importance of the IEP. The special needs assistant has an important role to play. A special needs assistant can observe communicative behaviours in depth and assist in modifying established programmes in the classroom to suit the educational needs of the child who is congenitally deafblind. As there may be no 'typical' individual who is deafblind (due to various factors, aetiology and degree of vision and hearing impairment), early intervention in the area of communication and language for this population may be supported by modes unique to the individual (like the repetitive sign routine in this case).

This research highlights the importance of considering an individual's particular needs and abilities when identifying an appropriate educational setting and when monitoring the progress of individuals with multi-sensory disability. This research will be of relevance to those working in education and support services for children with special educational needs.

Acknowledgements

The name 'Amy' is used throughout this paper and is not the real name of the girl involved in this study.

Chapter One *Introduction*

1.1 The distance senses and communication

The cognitive system predominantly relies on two senses in order to take in information from the environment: vision and hearing. These are referred to as the distance senses and they allow the mind to acquire information from the environment without making direct contact with objects and entities within the environment. These two senses play a vital role in communication and the acquisition of language. Natural language is speech, and auditory access to the sound units of speech (phonemes) is key to early language comprehension and production. However, vision also plays a vital role in language processing and in communication. We use visual cues such as facial expressions, facial movements and gestures to make sense of much language. Infants rely on vision for access to the key social precursors to language acquisition; for example, visual cues may allow shared attention between parent and baby, signal turn taking or confirm mutual understanding. These visual cues play an important role in communication long before language itself is acquired. The availability of visual and auditory stimuli is therefore assumed, to a great degree, in early adult–child and child–child interactions. Much communication is guided via the visual and auditory processes. The child with significant visual and auditory deficits faces immediate and lasting disadvantages that affect many aspects of the potential for language. From the very beginning, there is a 'mismatch between the immediate behaviour repertory of the congenitally deafblind child and the reactive behaviours of the adult population' (Nafstad and Rødbroe, 1997, pp.165-166). However, as Hart (2006) reminds us, '[a]ll congenitally deafblind people are potential communication partners. The key question…is how to help them achieve that potential' (2006, p.264).

1.2 What is deafblindness?

Deafblindness involves substantial impairment of both vision and hearing and is sometimes referred to as dual-sensory or multi-sensory impairment. The degree to which each of the senses is impaired differs from individual to individual. A common misconception is that deafblindness is a total inability to see and hear. In reality, the term covers a spectrum of combinations of varying degrees of vision and hearing loss. A total absence of vision and hearing lies at one end, while at the other end, residual vision or hearing, or some residual facility in both senses, is possible. In all cases, the hearing and visual impairments occur to a degree that precludes compensation for the weaker by the stronger sense; in other words, the person cannot function as might someone who is deaf or as someone who is blind.

Some people who are congenitally deafblind will be able to use their residual sight or residual hearing to support communication. In such cases, different types of communication methods are required than those that are useful for people with complete vision and hearing loss. Residual sight allows someone to avail of picture cues and visual signing, while those with residual hearing may benefit from audio language augmentation devices.

1.3 Congenital and acquired deafblindness

The pattern of visual and hearing deficit varies further with aetiology. There is a number of causes of deafblindness and some aetiologies bring associated difficulties additional to the visual and hearing deficit. The numerous aetiologies of congenital deafblindness add to the complexity of the condition.

Deafblindness can be acquired or congenital in origin. The implications in terms of prospects for language, social development and functioning differ in these groups, as do the associated needs. Acquired deafblindness occurs when a person becomes hearing and visually impaired during childhood or in adulthood. With an ageing population, increasing cases of dual-sensory loss in old-age are reported. Individuals with acquired deafblindness may have already attained symbolic communication or, indeed, may have acquired language before the onset of their sensory difficulties. By contrast, individuals who are congenitally deafblind are hearing and visually impaired from birth (or soon thereafter). Severe infections in early childhood can cause similar deficits and bring similar implications as apply for those affected from birth. The opportunities for acquiring communication skills are severely limited for this group and intellectual disabilities are often present. Early attempts at communication may be idiosyncratic and may be discontinued if they do not predictably lead to responses. Pre-symbolic gestures and body movements, which may be an attempt at communication, are often not interpreted as such and will perhaps fail to evolve into more abstract forms. Therefore the progression towards symbolic or formal language is often hindered. Where use of such symbolic forms (Braille or Irish Sign Language) occurs, it is often limited. This presents unique challenges not only for the person who is deafblind but also for professionals providing educational and support services.

Some causes of congenital deafblindness include premature birth, pre- and post-natal trauma, and viral infections such as rubella. Many adults who are deafblind were affected by the rubella virus *in utero*. Rubella can also cause neurological impairments, the precise nature of the influence depending on when the virus attacked the developing foetus. Since the introduction of vaccination, cases of deafblindness caused by rubella have reduced substantially. Today premature birth and pre- and post- natal trauma are more common causes. Genetic conditions can also cause deafblindness. For example, Usher syndrome leads to hearing loss from birth and loss of vision subsequently (often during childhood) as a result of the eye condition Retinitis Pigmentosa (RP). Many children with deafblindness present a range of additional difficulties, depending on the underlying aetiology. Severe learning disabilities may be evident, or conditions such as epilepsy may co-occur. There may be severe physical disabilities, further limiting the child's mobility. Other physical problems (e.g. feeding problems) bring additional challenges. Without early intervention and stimulation, the isolation experienced in the early years has a further negative impact on the potential for language and communication.

1.4 Strategies for communication

Although specific challenges face each deafblind individual in his or her efforts to acquire language, educational strategies have been developed to assist in optimising

language potential. Hart (2006) provides a useful historical overview of the progression of thinking around deafblind education. Between 1800 and 1950, the role of the teacher was emphasised as one of 'transferring' knowledge from the world to the deafblind child. A second period, from the 1950s to the late 1980s, saw efforts to foster communication become increasingly based on emotional bonding and related interactive routines. During this time, a focus on the acquisition of a symbolic language system came to the fore. Hart (2006) points out that methods focused on trying to teach the deafblind person so that they would communicate in a way consistent with that of hearing and sighted people. The use of tactile calendars, for example, appeared at this stage. However, *declarative communication,* that is when someone relates their experience to someone else, was rarely observed (Hart, 2006, p.265). From the 1990s, the focus returned to the ways in which communication was attempted with a deafblind person, with particular attention to co-activity, imitation and contingency of responses. Educational strategies for promoting communication and language in this population generally advocate an individualised approach (see McInnes and Treffrey, 1982; Van Dijk, 1986; Nafstad and Rødbroe, 1999; Chen and Downing, 2006). A need to encompass many different methods of communication, such as gestures, sign language and tactile signs, tangible objects of reference, or even speech, is apparent when supporting language acquisition. Two of the most common methods used in Ireland are sign systems and tangible objects of reference.

1.4.1 Sign Systems

One type of sign system used is *formal sign language* such as the system of Irish Sign Language for the Deaf (ISL). ISL involves a one handed alphabet, with approximately 1,600 signs demonstrated in the dictionary. Some signs in the vocabulary are similar to the movements used in the activity they represent and have origins of a gestural nature. For example, the sign for 'swimming' uses a breaststroke-like mime. Another branch of formal sign language used in Ireland is Language Augmentation for the Mentally Handicapped (LAMH) with communication difficulties. This vocabulary was developed as an easier alternative to the more abstract Irish Sign Language, and arose from a need to have a unified and simplified approach for those with intellectual disabilities. Although LAMH is closely connected to ISL, it has adapted signs to be more representative of the activity or object they represent. LAMH also emphasises the use of simple hand shapes and the incorporation of gesture in the development of a vocabulary. By definition these signs seem quite similar to adaptive signs (see below), although they are perhaps more unified within a system.

Adaptive signs are defined here as those agreed upon by family members or individuals who work with the deafblind person. These signs emerge through use and may differ from agency to agency, or from family to family, and can undergo modification with use. Adaptive signs may be a type of transformation of a formal sign, altered so as to be easier for the deafblind individual to understand. They are often chosen because they are closely connected to the activity they represent, in the hopes of providing a ready association with the activity. These signs usually involve a motor depiction of the activity; for example, a sign for 'music class' might involve the use of a drum, or could be represented by the action of banging the palm of one hand with the index finger of the other in order to simulate the banging of a

drum. Adaptive signs are not unique to one individual but are based on an interpretation of what individuals (teachers, care staff or family – not necessarily the deafblind person) perceive the activity to be. These adaptive signs are chosen from close observation of the deafblind individual when engaging in an activity.

Natural gestures are individually motivated signs, and involve a re-enactment of an experience with the body (Robbins, 1983). A natural gesture comes from the deafblind individual's own movements and grows into a gesture as it comes forth naturally. Someone who is deafblind will not represent aspects of an event in the same way a person with sight and hearing would perceive it, but would refer to it as an impression received from the event through direct contact or impression on the body (Nafstad and Rødbroe, 1999). An event could be perceived based on any of a set of relevant features; for example, the adaptive sign for 'music class' could be similar to the activity of banging a drum, but the natural gesture could be anything from raising the foot (because vibrations are felt through the feet when banging the drum), to making a fist with the hand (because that was the way the drumstick was held when the drum was hit). These gestures vary among individuals who are deafblind and interpretation of their meaning is dependent on having knowledge or experience specific to the situation (Robbins 1983) or indeed to the individual. The spontaneous gestures described by the Deafblind International Communication Network (e.g., Daelman et al., 2004) called *Bodily Emotional Traces* (BETs) place emphasis on the emotional impact an experience has on an individual. Through the affirmation of these BETs by a communicative partner, a meaningful exchange may develop. Often, natural gestures are not interpreted or they are mistaken for stereotypical behaviours. Nafstad and Rødbroe (1999) suggest that the meaning of these natural gestures must be negotiated through steps, which can be repeated in co-constructing a shared vocabulary. Different methods of signing can be used to create a shared experience. *Co-active signing* refers to sign language that is assisted by another communicative partner. *Contact signing* is sign language that takes place with one hand while the person who is signing uses the other hand to make contact with another person, an object or a part of their own body.

Routines or ritualised patterns may be evident in the use of sign systems by individuals who are deafblind. Echolalia (involving signs instead of speech) and imitation rituals are commonly exhibited by individuals who are deafblind, and these may be central to their efforts to communicate rather than being maladaptive stereotypes as is sometimes suggested. An individual may respond not with an original response, but with the same sign that was just signed to him or her. This may seem problematic when family, teachers or support workers try to engage in conversational discourse, as communication is hindered by the lack of dialogue. Since stereotypic behaviours are often utilised when advancing communicative interaction in many deafblind educational strategies, routines within signing could be regarded as serving a similar function to such behaviours, and may be stepping stones towards developing language.

1.4.2 The use of objects of reference

The use of tactile objects may also provide a bridge into communicative interaction and allows understanding of the environment through the haptic sense. A vocabulary can be introduced by using tactile objects as a system for communication. These

objects are called *objects of reference* or tangible symbols.

Objects of reference are objects that refer to other objects, activities, places or even people. For example, a link of chain can be representative of a swing (or the activity of going on a swing), a cup can be representative of the activity of having a drink, a swimming armband can be representative of going to the swimming pool. Different people can be identified by personal objects, such as a pair of eyeglasses or a piece of jewellery. According to Rowland and Schweigert (1989, 2000), tangible symbols make relatively low demands on cognitive processing in the following ways. As they are permanent, there is no necessity to recall from memory; instead, the less effortful cognitive processes underlying recognition memory may be used. They are manipulable, that is they can readily be handled, manipulated, and exchanged physically. They are tactually discriminable, so that the referent is clear when the person touches the object. They are iconic in that they maintain a close relationship to their referent. Finally, they require only a simple motor response in order to be utilised effectively.

Meaning is acquired as follows. Initially, an association is made when the particular object is always involved in the activity and over time the object comes to characterise that activity. These objects are what Aitken (2000) calls 'object cues' and they differ from objects of reference by their symbolic qualities. An object cue is a particular object or place that is always involved in an activity and acts as a signal for the occurrence of certain events. For example, putting an art smock on might signal that it is time for painting class, or sitting on a certain mat in the bathroom in order to take one's shoes and socks off might signal that it is time for a bath. Once the cue is separated from the real event, both in time and by use of a different object than that being referred to, it is an object of reference (Aitken, 2000). McInnes and Treffrey (1982) use the term 'class cues' to suggest a series of coming actions; for example, when a person feels a piece of towelling outside of the context of a bathroom, she/he will still understand the association with bathtime. Once aware of the referential function of an object, one can learn to refer to the activity in question by taking the object or using a schematic shape of it as a reference (Van Dijk, Janseen and Nelson, 1993). Like words, these objects of reference become the vocabulary of the deafblind individual. Individualised selection is key when choosing objects. An event or a person is represented by a particular symbol that is distinctive for that particular child (Jurgens 1977; van Dijk, 1986; Aitken, 2000; Chen and Downing, 2006) and is generally related to a bodily impression. What may seem like an obvious representation may not be obvious for a particular deafblind individual. When using an object, the features or main characteristics that identify it should be emphasised.

These objects become more abstract and symbolic when using miniature forms of the object or parts of the whole object; see Figure 1 for an example. A cup that represents having a cup of tea might now be represented by a miniature doll's cup or perhaps a handle of the cup. Miniature objects are more likely to be successfully employed if the individual has established skills in representative play or has good receptive language. A more obvious link to the experience is created by picking out the critical features for each individual, when using parts of objects in developing more abstract forms (Aitkin, 2000).

For deafblind people with residual sight, abstract forms can be represented by a photograph or a drawing. At first the drawing or photograph might be the same size and colour as the real object; subsequently, its representation can become more abstract such that a smaller, partial, or black and white image would be effective. Foam cut-outs that represent whole objects, parts of objects, or even miniatures (see Figure 2) can be used. Tactile pictures or cards can be made from raised outlines of objects; these can be handmade or made using an embossing machine. Arbitrary tactile symbols, which are representations made from fabric or textured paper, are utilised in representing abstract concepts, such as the days of the week. This type of symbol is predominately used as part of a calendar system, to communicate activity planning as part of a schedule of activities.

These levels of representation are similar to the three described by Park (1997): icon, index and symbol. An icon has a strong physical resemblance to the object it refers to (a photograph or partial object for example). An index has an association with the referent but not a direct physical resemblance; for example, car keys might be used to refer to a trip in a car. A symbol is an arbitrary representation and has no physical resemblance to the object it refers to (a spoken word or an abstract sign for example).

Symbolic representations can often be 'distorted' for those who are deafblind. The progression from concrete to more abstract, arbitrary and symbolic forms is challenging. Careful attention must be placed on ensuring understanding of the connection between the object and what it represents. When successful, this can pave the way for more abstract language skills, such as learning the alphabet or using Braille. Individuals with deafblindness must also have valid experiences to utilise when making this connection or there is a risk of developing *empty forms* (Blaha, 1999). For example, learning to memorise abstract Braille words may occur through repetition without the valid experience of the word meaning. A symbol system is used for thought as well as communication, but 'a symbol system used only for communication, like Morse code, is not a language' (Harman, 1987, p.57). It is common to see a mixture of different levels of symbolisation – for example objects and pictures or foam cut-out representations and Braille – in a communication system for an individual, as well as methods changing over context. Progress is easier when new information is presented with concrete symbols and abstract forms can be attempted for more familiar information (Blaha, 1999).

It is often beneficial to use sign systems in conjunction with objects of reference. By reinforcing the signs and the objects together, a stronger connection is made, strengthening the symbol's meaning. The use of sign language and objects of reference involves what Blaha (1999) describes as both *static* and *dynamic* forms of symbols. Static forms are tangible forms that can be referred to at any time, such as objects of reference, tactile symbols and written forms like Braille. These forms can be referred to for as long and as often as the individual needs them. Dynamic forms are those that provide information immediately, disappearing as soon as they are produced. Dynamic forms of symbols include spoken words, signs, finger spelling and gestures. When an individual who is deafblind wants to refer to a message that was previously conveyed, he or she would have to retrieve it from memory or ask the message to be repeated if expression has used a dynamic form. Thus more cognitive effort is required in utilising (producing or understanding) the dynamic form

of a symbol. Because static forms require less effort, objects of reference assume a facilitative role when used with sign systems and encourage further language development.

Figure 1. Part of a cane used as object of reference for mobility training

Figure 2. Cut out of a bus used as reference for a trip on a bus

1.4.3 Calendar systems

Calendar systems aid the person who is deafblind in structuring activities and interactions with the environment as a function of time (e.g., activities the person can expect over a day, in the following week, etc.). Fulfilment of the need for security is fundamental for the social and emotional development of the deafblind person (van Dijk, Janseen and Nelson, 1993). A schedule or calendar system (see Figure 3) can be devised by using objects of reference to inform individuals with deafblindness of the activities that will occur throughout the day. In a world where environmental stimuli are perceived in an atypical and unpredictable manner, calendar systems are a useful method of relating to people and objects in the environment (van Dijk et al., 1993). The number of objects presented and the amount of information thereby communicated will depend on the capabilities of the particular individual. For example, a person might be directed to touch three objects of reference – a cup, a swimming hat and a spoon – in that order. The individual will then know that she or he will have a cup of tea first, then go swimming, and then have lunch (the cup representing a cup of tea, the swimming hat representing swimming, and the spoon representing lunch). Each object of reference is further associated with its meaning, depending on the level of memory of the individual, by physically bringing the object with them to the activity. When the individual is finished the activity, he or she returns with the object and puts it in a special box called a *finished box.* This reminds the individual that she/he is finished with that activity and is ready to go on to the next one. The quantities of objects that are introduced depend on the aptitude of the deafblind individual. Each calendar system can be adjusted to suit the individual's

own capabilities. As an individual becomes adept at using a calendar, one can advance systematically across a variety of time frames, through a daily or weekly calendar, as applicable (Blaha, 1999)**.**

Educational strategies can use objects of reference for creating dialogue with deafblind individuals. Conversations can be established and maintained by representations in book form or in storyboards. Experiences can be communicated and relived by the deafblind individual by using the objects of references as cues. Sign systems can be used in conjunction with objects in order to promote, and assist with, dialogue. A discussion book or a three-dimensional scrapbook (see Figure 4) can be prepared by using familiar objects from a particular activity. A discussion of this kind allows the individual to reflect on an event that happened in the past. The key is to use what the individual finds motivating in the given situation and use that object as a reference to effect a conversation about shared experiences (Miles and McLetchie, 2004).

Figure 3. Part of a weekly calendar system

Figure 4. Dialogue book with cut-out representations of a story

1.4.4 Imitation

In recent years, imitation has been identified as a potential means of communication for the deafblind person. Bruce (2005) identifies imitation as one of several developmental markers or milestones that support the development of symbolism or abstract representation necessary for language. Hart (2006) identifies four key functions that imitation may serve toward this end. First, imitation attracts attention and serves as a 'powerful mechanism for obtaining, sustaining and even regaining interpersonal togetherness' (Hart, 2006, p.268). He notes the immediate confidence-building effect of recognising that one has a means of attracting the attention of a potential communication partner. Imitation serves to support a joint dyadic pace (see Rødbroe and Souriau, 2000). Second, imitation stimulates turn-taking, in that the

repetition of a behaviour by the partner leads to a turn-taking exchange. Turn-taking is known to play an important role in language acquisition for typically developing children (e.g., Stern, 1985). Hart's third function of imitation involves the recognition of the communicative partner by the deafblind person. Patterns of repeated behaviours can build up over time into a ritual or indeed a greeting. Finally, Hart notes the role of imitation in developing the recognition of the communication partner as a like-minded other, essentially promoting a 'theory of mind' in the deafblind person. Receiving an imitative response allows the deafblind individual to appreciate a 'like mind' in the other person and to thereby begin to attribute intentions, emotions and thoughts to the other person.

Imitative sequences may utilise repetitive behaviour of a type that is sometimes argued to be unconstructive. Repetitive behaviours similar to those seen in autism are commonly observed in people who are deafblind and are argued to occur as a direct consequence of sensory deprivation (van Dijk, 1982). The cognitive systems that allow us to orient, react and habituate to stimuli within our environment come to be directed toward inward stimulation, in the absence of sensation of stimuli coming from the outer world via the senses. Thus, self-stimulatory behaviours develop (van Dijk, Klomberg and Nelson, 1996). Some examples of these behaviours are twirling, eye-poking, slapping the face and flapping the hands. Individuals who are congenitally deafblind might spend many hours engaging in this type of behaviour, remaining in a 'reflexive' state (being self-engrossed, without interest in interacting with others).

Various strategies have been developed in an effort to try to reduce such behaviours. Murdoch (2000) examined the roles that these repetitive behaviours play in children's development as well as the strategies that educators utilise when interpreting and responding to them. She argued that these repetitive behaviours comprised three categories: 1) self-directed, stereotypical behaviours; 2) delayed, developmentally normal behaviours; and 3) functionally equivalent behaviours. She found that the best educational approach varied with the individual child, the type of behaviour and the type of situation the behaviour occurred in. It has been argued that these behaviours might form the basis for communicative interaction. Although an eclectic approach may be necessary, a central theme involving utilising these behaviours as early foundations of interaction is present in many contemporary strategies for the development of communication skills for individuals who are deafblind (McInnes and Treffrey,1982, van Dijk,1986; Nafstad and Rodbroe,1999; Janssen et al, 2003).

Therefore what may start out as repetitive or imitative sequences can develop meaning over time and lead to effective communication. Furthermore, such behaviours can motivate meaningful communication. Helen Keller (though not a typical case), in *The Story of My Life* (1905), makes a related observation. She describes being given a doll by her teacher, Anne Sullivan, who spelled the word 'd-o-l-l' into Keller's hand: 'I was at once interested in this finger play and tried to imitate it… I did not know that I was spelling a word or even that words existed; I was simply making my fingers go in monkey-like imitation' (Keller, 1905, p.35). In Keller's account, meaning followed the signed behaviour, which was repeated many times before comprehension of linguistic labels was attained, an account consistent with Vygotsky's (e.g. 1978) approach to cognitive development. Vygotsky's account

stressed the role of social interactions in language development and considered how the social environment provided psychological tools that aid development. Vygotsky (1978) also introduced the concept of a 'zone of proximal development', representing the potential for achievement by a child through interaction with an adult or a more advanced child, and suggesting a 'knowledge gap' between what might be achieved alone and in interaction with another. This knowledge gap is potentially vast for those with deafblindness, particularly if early intervention is not forthcoming.

1.5 Key questions

What are the best techniques to use so as to maximise language potential for those individuals who are congenitally deafblind? How can such educational strategies be implemented so that they provide greater communicative competence to support integration? What systems may be put in place in designing an Individual Education Plan (IEP) that considers the unique communicative capabilities of an individual who is congenitally deafblind?

This research paper looks at the abilities of one particular child and follows her communicative progress over a nine month period in order to gain an insight into such issues. Research on the communicative ability of individuals who are congenitally deafblind benefits from long-term, longitudinal observations and, as observed by Verloed, van Dijk, Knoors and van Dijk (2006), must be videotaped as 'otherwise it is extremely difficult to notice all the potential communicative signals exhibited by the deafblind child' (2006, p.337).

In this study, we were particularly interested in the development and functions of a particular sign routine or sequence, with imitative qualities, used by the girl (who is referred to as 'Amy' in what follows). We videotaped Amy across a range of activities and interactions and transcribed and coded key events and interactions. The transcriptions were examined for a range of communicative and language functions, with particular attention to the representation of body-environment interactions, and the repetitive use of a signed routine. This repetitive routine is examined with respect to its content and its possible functions.

1.6 A Case Study: Amy

1.6.1 Background

'Amy' is an adolescent girl, aged 13 years at the time of the study. She was born in a hospital in Eastern Europe and, according to the limited records available, was premature, being delivered at twenty-six weeks. She lived in an orphanage in her home country until she was adopted by a family from Ireland at the age of seven years. She has been living with her adoptive parents in Ireland for the past seven years. Although records of her early years provide little detail of her early development, it is likely that she experienced little by way of specialised care and indeed may have been deprived of stimulation during those years. Personal accounts suggest that the staff–child ratios in operation at the orphanage would not have been conducive to individual attention. Poor nutrition may also have impacted on Amy's early development. When Amy arrived in Ireland, she was physically

underdeveloped, had no communicative abilities and exhibited some stereotypical or reflexive behaviours. However, residual hearing was apparent even at this early stage and thus auditory input may have played a key role in stimulating Amy's early development. It was clear that she could hear certain environmental sounds; it was less clear whether her remaining hearing allowed speech perception at that point.

As a result of her premature birth, Amy has combined vision and hearing loss. The vision loss is near complete, but Amy's residual hearing allows her to benefit from wearing hearing aids and she uses a micro-link system at school. She has enough residual hearing to be able to hear some simple utterances. She can carry out some functional skills, such as toileting, dressing and showering, although some assistance is needed. Some issues have arisen with regard to her eating, but for the most part she is able to feed herself independently. Extensive training in developing her feeding skills (pouring and using a knife and fork) has been implemented as part of her educational programme. She is able to move independently around her home, requiring little assistance. She is learning how to walk with a cane under the guidance of a mobility instructor.

Amy attends a special school for children with moderate to severe physical and learning disabilities. She has her own teacher in a self-contained classroom which is attached to a larger class within the school. She spends time in individualised instruction within the self-contained class and attends group work and break time in the larger class, along with other students. The students in the larger class have learning disabilities and do not have multi-sensory impairments.

1.6.2 Communication history

Amy uses a combination of various types of sign systems, ranging from Irish Sign Language (ISL), LAMH, the Deafblind Manual, adaptive signs, and natural gestures. Recently, Amy's teaching programme has focused on teaching Amy LAMH signs, both in the school and at home. Amy now has approximately twenty-five signs in her vocabulary.

Amy uses a weekly schedule calendar system at school with a combination of miniature objects, parts of objects, cut-out representations, alphabet letters and Moon alphabet letters. Continuity of use was established between school and home by sending objects of reference back and forth in order to explain what Amy did at home or at school. Tactile representations were also used, in diary form, as another link between home and school. Efforts were previously made to introduce Amy to the raised cut-out representations of the Moon alphabet but these have now been replaced by cut-out representations of the Roman alphabet. Amy still uses a Moon alphabet representation of her name.

1.6.3 Amy's signing routine

Amy's teachers report that she started to sign two years ago in a 'routine-like' manner. She would use five signs in a routine sequence with six items. The routine consisted of a sign sequence translating to: *tea, biscuit, tea, bread, swimming, Okay*. When Amy first started the routine, she would produce it up to forty times during the day, with thirty to forty uses on average per day. This routine would

principally occur when Amy was at home, and mainly when she was spending time with her mother. Amy also signed this routine with her teacher at school as well as with a special assistant who escorted her on the bus home from school. As use of the routine progressed, Amy would use verbal feedback from the communicative partner as she signed, waiting for someone to say the sign before she continued. In this way, the communication partner imitated verbally what Amy had just signed. Questions concerning the value and function of this routine in promoting communication were often discussed by her parents and teachers.

Chapter Two *Methodology*

Since commencing this project in January 2007, observations of Amy have taken place over nine months within a one year period (January-July, September-October). In all, eleven visits were made, each lasting one to two days. On each day several hours of video recording occurred. On each visit, Amy was video-recorded taking part in a diverse range of activities in her school as well as at home. Activities at school were structured and ranged from taking part in a special cooking class to doing art projects with her classroom teacher. Activities at home were more flexible and revolved around interactions with her mother. Approximately 200 video clips were collected over the period of the study. A description of each video clip was documented and the clips that contained some type of communicative exchange (e.g. use of gesture, sign language, or tangible objects of reference) were transcribed using a modified version of Jefferson's (2004, pp. 24-31) transcription system. This method emerged from research in the area of conversation analysis and was found to be useful here. Forty-one representative clips have been transcribed from the data collected. The limited communication restricted the number of clips that were transcribed, as many videotaped segments did not include any communicative behaviours. This is a noted problem when conducting research with this population. Vervloed, van Dijk, Knoors and van Dijk (2006), examining communicative interactions between a congenitally deafblind child and his teacher, found that just 2 per cent of recorded activities contained communicative interactions that could be coded, despite choosing (as we did here) activities that were likely to lead to communicative interactions (e.g., playing, dressing).

2.1 Categories

The following types of communicative act (e.g. gesture, sign language, objects of reference) were coded in the forty-one clips. The behaviours were coded using the following categories:
1. **Touch clues:** touching an object or a person as a reference
2. **Iconic or Miming Gestures:** a gesture depicting a motor activity (not already a part of a formal sign system)
3. **Deictic Gestures:** pointing gestures
4. **Modulator Gestures:** gestures used to confirm, negate or indicate doubt (e.g. nod)
5. **Bodily Perceived Gestures:** natural gestures, gestures relating to an experience perceived on their body
6. **Object of Reference Type 1:** a real object representing a person, activity or another object
7. **Adaptive signs:** use of a sign that has been invented and is not part of a sign system. These can be iconic in quality or arbitrary
8. **Formal Sign Language:** Irish Sign Language, LAMH or Deafblind Manual
9. **Objects of Reference Type 2:** using part of an object or miniature version of an object
10. **Objects of Reference Type 3:** using cut-out drawings or photographs. These could be characterised as being cut-outs of miniatures or parts of an object or as being cut out of a depiction of the sign
11. **Arbitrary tactile symbols:** tactile representations
12. **Formal Written Language:** Alphabet, Braille, Moon.

Using a modified version of the categories defined by Nichols et al. (1999, 2003), judgements made regarding functions of communicative acts were coded as follows:

1. **Directives:** acts used to direct the intervener's attention or action;
2. **Markings:** acts used to mark attentiveness, emotion, an event, or agreement/disagreement;
3. **Statements:** acts describing a past or present activity;
4. **Responses:** acts made in response to an intervener's question; some responses may not be consistent with what was requested but an attempt was made to respond;
5. **Questions or Requests**: an act that comprises a request or a question;
6. **Undecided**: coder uncertain as to type of function.

2.2 Coders

Two experienced teachers for the deafblind coded the behaviours in the video clips. The coders were selected because they had at least five years' experience in working in the field of education for the deafblind and had expert knowledge in the area of sign systems utilised by the deafblind (e.g. ISL, LAMH, adaptive signs) and in the area of objects of reference or tangible symbols. Both coders have received formal training in communication strategies at international workshops.

The coding process is difficult when individuals are functioning at a pre-linguistic stage of communication, since so many behaviours likely to be communicative are idiosyncratic or unconventional. Nichols et al. (1999) argue that disagreement among coders should be analysed in order to provide an accurate account of communicative competence.

Chapter Three *Findings*

From the 41 clips transcribed, inter-rater reliability was high, with 99 per cent agreement on the overall content of transcripts. The average level of agreement on the types of behaviour that were exhibited in the transcripts was 91 per cent. Across the 41 clips that were transcribed, 74 acts were coded, the most frequent type being 35 instances of formal sign language. There were also nine instances of modulator gestures, ten instances of bodily-perceived gestures, six instances of using objects of reference (type 2), four instances of formal written language, three instances of adaptive signs (iconic), five instances of using objects of reference (type 3; three were miniatures and parts or objects and two were cut-out depictions of a sign) and two instances of deictic gestures.

Coding for communicative functions went as follows: 42 per cent of the 41 clips were coded as *Responses only*, 16 per cent were coded as *Markings only*, 5 per cent were coded as *Directives only*, 5 per cent were coded as *Statements only*, and 3 per cent were coded as being *Requests*.

Of the 41 clips, 20 per cent were coded as having more than one function: 8 per cent as *Statements* and *Responses*, 3 per cent as *Markings* and *Statements*, 3 per cent as *Markings* and *Responses*, 3 per cent as *Directives* and *Statements*, and 3 per cent as *Responses* and *Undecided*.

The other 9 per cent of the 41 clips made up combinations of three functions: 3 per cent as *Markings*, *Statements*, and *Responses*, 3 per cent as *Markings*, *Requests* and *Responses*, and 3 per cent as *Directives*, *Markings* and *Responses*.

3.1 Changing communication over the period of study

The 41 transcribed clips were divided into three time periods over the nine months of the study. The first stage (Time 1: January – April) involved 14 clips. The second stage (Time 2: May-July) involved eleven clips. The third stage (Time 3: September-October) yielded 16 clips. Out of the 74 types of communicative behaviours that were coded, the first section contained 24 coded acts, the second section contained 22 coded acts and the third section contained 28 acts. While each time period is generally comparable in terms of the types of activities observed, changes across the time periods must be interpreted with caution, as opportunities to observe Amy were dictated by practical considerations and, given the observational nature of the study, many variables were outside the researchers' control.

At Time 1 (24 coded acts), there were 12 instances of formal sign language, five instances of modulating gestures, three instances of bodily perceived gestures, one instance using a deictic gesture, two instances of using adaptive signs, and one instance using formal written language.

At Time 2 (22 coded acts), there were eight instances of formal sign language, six instances of using object of reference (type 2), two instances of using modulating gestures, two instances of using formal written language, one instance of using an object of reference 3, one instance of using a deictic gesture, one bodily perceived gesture, and one instance of using an adaptive sign.

At Time 3 (28 coded acts), there were 15 instances of formal sign language, six instances of bodily perceived gestures, four instances of using objects of reference, 2 instances of using modulating gestures, and one instance of formal written language.

Formal sign was the most frequent type of communicative act, with at least 30 per cent of coded acts in each time period falling into that category (see Figure 5). At Time 1, 13 per cent of the acts were bodily perceived gestures which decreased to 5 per cent at Time 2, but increased at Time 3 to 20 per cent. The modulating gestures decreased over the three time periods. Objects of reference Type-2, which are parts of objects or miniatures, were only accounted for by 25 per cent of the coded acts at Time 2. The use of objects of reference Type-3, a more abstract type, increased to 15 per cent of the acts coded at Time 3, from 5 per cent at Time 2. Five per cent of the communicative acts were deictic gestures at both Times 1 and 2, and none were coded at Time 3. Eight percent of the communicative acts were adaptive signs at Time 1, with 5 per cent at Time 2, and none were coded at Time 3. At Time 2, 10 per cent of the acts were coded as using formal written language, while at both Time 1 and 3 only 3-4 per cent of the acts were coded as such.

Ten representative clips were selected from the research data in order to analyse the possible functional properties of a repetitive sequence that Amy used. Out of the ten clips that were selected, seven of the clips were from footage collected at home with her mother. The other three were recorded at school. The number of signs exhibited increased over the ten clips, from the six signs in the core sequence initially in the first clip to over 30 signs by the tenth clip. These longer sequences do not involve over 30 distinct signs; rather there is repetition of some segments but there is also vocabulary additional to the core routine (eleven signs). The basic or core routine consisted of five signs in a fixed sequence of six items (*tea, biscuit, tea, bread, swimming, Okay*). The possible functions of this routine are discussed in the following section.
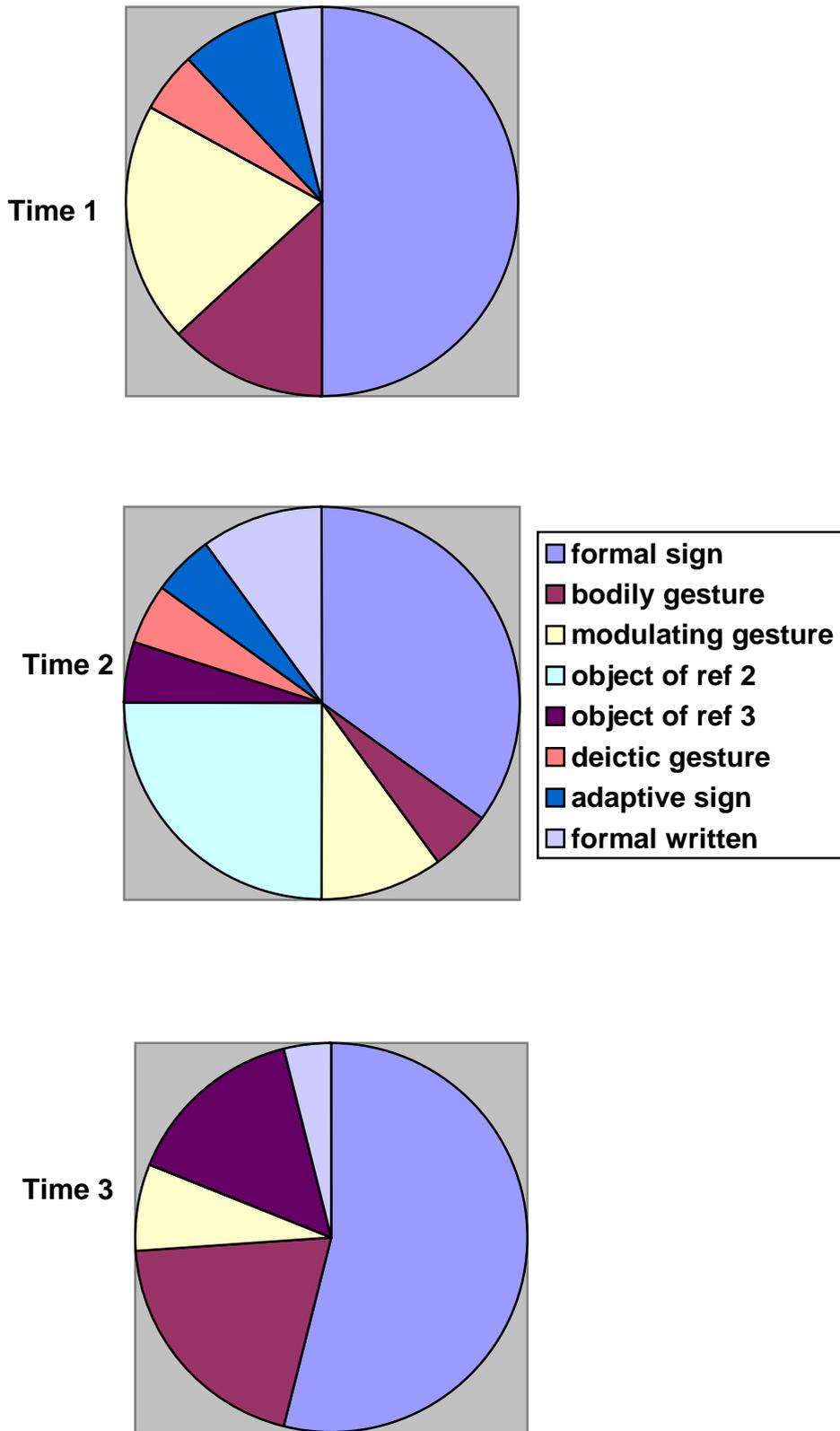
Figure 5. Proportion of coded acts across the three time periods (Times 1-3).

Chapter Four *Discussion*

The developing use of **sign language**, especially the use of formal sign language, is evident in the data. Almost half of all communicative behaviours (47 per cent) occurred through the use of some type of formal sign language, be it ISL, LAMH or the Deafblind Manual.   Many of the signs used as part of Amy's repetitive routine (*tea, biscuit, tea, bread, swimming, Okay*) are formal signs. Over the course of the study, the repetitive routine increased in terms of both sequence length and vocabulary, with additional formal signs featuring within the routine. Bodily perceived gestures were also evident, in addition to the formal signs.

Three word sentences appeared within the routine, suggesting grammar development within Amy's signing. As occurs in early grammar development in verbal children using two-word utterances, Amy's sentences contained *pivot-open grammar*, with patterns of pivot words and open words (Braine, 1963, cited in Harris and Coltheart, 1986) embedded within the sign routine. For example, she used the phrase 'I love' as one pivot followed by one of a number of nouns (e.g., *swimming*). The repetitive routine appeared to provide opportunities for Amy to practise using her sign vocabulary and it increased the capacity for new signs to be introduced.

Modulating gestures (e.g. nods and headshakes) were apparent in nine out of the 41 clips.   These gestures were used when responding to verbal questions. Modulating gestures require less cognitive effort to produce than signs. It is easier to respond with a nodding gesture when asked 'Do you want a drink?' as opposed to initiating a sign.

In the video clips, Amy used **deictic gestures** to refer to something she wanted but did not have a sign for. In one clip she is seen pointing directly at the fridge. Through negotiation her mother deduced that it was chocolate in the fridge that Amy was referring to and she acknowledged her efforts by asking Amy 'Do you want the chocolate?' This became an opportunity to practise the sign for chocolate. Objects or events that Amy referred to by pointing were usually reinforced verbally with a word or by the introduction of a new sign. Deictic gestures therefore appear to play an important role in helping to introduce new signs into her vocabulary.

Amy also started inventing her own signs, especially when doing activities at home. These signs (or **natural gestures**), adopted by her mother, are based on aspects of an object or activity that are relevant for Amy herself. Ten out of the 41 clips were coded as **bodily perceived gestures**. Many of the clips that contained these types of gestures were from footage collected in the later months of the project. These bodily perceived gestures appeared after Amy had gained confidence using formal signs. Usually bodily perceived gestures occur during the beginning stages of language development of many deafblind educational strategies; in this case, bodily perceived gestures followed formal sign. These gestures seem to have emerged when Amy realised her own communicative ability, via feedback through her use of formal sign language. Through consistent use, these bodily perceived gestures have become part of Amy's repertoire of signs along with her use of formal sign language.

Three instances of **adaptive iconic signs** were also seen. These iconic gestures, although they are not based on Amy's perceptions of an event, occurred as a

motoric depiction that was easy for her to understand. For example, one of the signs (jumping up and down on the spot) was chosen to depict one of her favourite activities of bouncing on a trampoline. Like the bodily perceived gestures, these adaptive iconic gestures have been successfully implemented within Amy's sign language vocabulary.

Tangible **objects of reference** and **tactile symbols** have been introduced in both daily calendar systems as well as in conversational books at school. Six instances were coded which featured use of objects of reference characterised as part of an object or as a miniature, and five instances using tactile cut-out representations of objects were observed. Even though formal sign language was the most frequent type of communicative act utilised, a slight decrease in use was evident within the study period (Time 2). This could be due to the increase in the use of **objects of reference** (Type 2) during this time. Objects of reference Type 2 are more abstract in representation (being miniature forms or parts of objects) requiring a higher cognitive level to comprehend. Emphasis on employing such objects of reference may have temporarily reduced the use of formal signs.

There were four instances of **formal written language**. Tactile cut-out representations of the actual sign have been introduced in Amy's diary books. For example; the tactile representation for the word love, as in 'I love swimming', is represented by a cut-out representation of an X. The X represents the way you hold your hands when you sign the ISL sign for 'love'. Such representations based on the way a sign is produced have been incorporated into dialogue books and diaries. Amy is able to reproduce the sign when she feels the tactile representation on the page, promoting tactile reading skills. Such books encourage dialogue with her teacher and also assist in discourse outside the classroom.

Functional aspects of the behaviours in the video clips were predominately coded as being responses and markings. Only a small percentage of the clips had elements of requesting, directing, and making a statement. Most of the clips were coded as involving a response either on its own or with other functions in the clips. This could reflect the difficulties for individuals who are congenitally deafblind in being able to initiate signs and the noted dearth of declarative communication (Rødbroe and Souriau, 2000). Many of the clips coded contained the question, 'Can you sign (a name of something)?' or 'What is the sign for (name)?' produced by an intervener (e.g. mother or teacher) which prompted Amy to respond with a sign and initiated or maintained dialogue in this way. These also served to establish whether Amy was paying attention. The fact that Amy used modulating gestures as well helped her to mark agreement with her communication partner.

For Amy, the repetitive sign routine often prompted interactions based on **imitation**. Particularly when using the routine with her mother, Amy seemed to be using it as a ritual to introduce an imitative interaction, and she waited on the imitative response to each sign before continuing with the sequence. In one clip, her mother mistranslated one of the signs. Amy re-signed it until her mother imitated it correctly, and it is only when she received that response that she continued with her routine. This repetition of the sign until it is understood would seem to provide evidence of intentionality as well as flexibility to adjust responses within the routine. Amy's persistence until her mother imitates her appropriately shows that she is acting with

the intention of communicating with her mother, with the intention of eliciting an appropriate response (see Bruce, 2005). She wants to be understood, even if, at this stage, the sequence of signs is not in and of itself particularly meaningful. The rapport, and the responsiveness of her communication partner, is salient to her.

While the sign sequence may initially have appeared to be little more than a reflexive act or stereotype, over time it can be seen to have become more like a tool in assisting cognitive processing. The repetitive routine provided opportunities for advancement to more symbolic communication by assisting the production of two to three word sentences. It could also be a useful device for the development of pragmatic or social skills, helping to cultivate and maintain ongoing discourse, to stimulate turn-taking, and so forth (see Hart, 2006).

Such modifications could be useful for those who struggle or who are delayed in developing more symbolic forms of language. Addressing the difficulties in acquiring symbolic language for the person who is deafblind, certain strategies or linguistic tools may be recruited in order to assist communication. One such tool could involve the use of familiar sequences to aid fluency, maintain contact with the other person and perhaps also to aid working memory by allowing the deafblind child to hold information in mind while manipulating it with the addition of novel information and signs. If the inclination towards repetitive sequences can be harnessed in this way it would seem to have potential to facilitate meaningful interactions with others and thereby support integration.

Chapter Five *Conclusions*

This analysis is based on an assessment of one individual with congenital deafblindness. She is, in many ways, not typical of this population and her residual hearing, in particular, may support language to a greater degree than can occur for those with less hearing. She is also less passive than is often the case and for this reason, attempts to engage her are more likely to meet with success. She therefore enjoys an atypical level of consistency in her interactions, and this will support attempts at communication. Intervention that may be appropriate for this child will not be appropriate for other children with similar conditions. In considering the following conclusions and recommendations based on the present data, the individual who is deafblind and his or her particular needs and aptitudes must be borne in mind.

The analysis offers the following suggestions towards supporting communication and assisting language development for those who are congenitally deafblind:

1. It is useful to observe and analyse individualised adaptations that may appear in sign systems. These could be stepping stones to more abstract levels of language and careful attention to individual communication methods is required in order to pick up on these attempts at communication.
2. Deictic (pointing) gestures may provide educational opportunities to introduce vocabulary. These might be encouraged through timely, appropriate and contingent responses, with new information offered as appropriate.
3. It is useful to acknowledge and cultivate natural or bodily perceived gestures. These gestures may lead on to more formal types of sign systems.
4. Combinations of different sign systems – formal, adaptive and natural gestures– should be used, as works best for the particular individual. Routines might be encouraged and flexibility within them facilitated in order to lead to novel responses.
5. Tactile representations should be tailored to the individual; for example, representations based on signs as opposed to objects may be suitable to those who may have proficiency in formal sign language.
6. Tactile representations or objects of reference (e.g., tactile diaries, tactile letters, object boxes) might be particularly useful for promoting continuity between home and school, and for supporting interaction with others at school.

Many of these points are not new and have been advocated in various methods addressing communication in those who are congenitally deafblind (see McInnes and Treffrey, 1982; Van Dijk, 1986; Blaha, 1999; Nafstad and Rodbroe, 1999; Chen and Downing, 2006). The recurring theme in promoting language for this population is individualisation. Educational strategies that rely on the use of sign systems and tactile objects of reference can prove beneficial, as long as those using them are aware of adaptations and modifications that may develop that are unique to the particular individual who is deafblind.

Early intervention is crucial for the development of language by people who are congenitally deafblind. Early attempts at communication must meet adequate responses in order to be nurtured. Attempts at communication that are atypical, if noticed, may be disregarded and opportunities missed for progression to symbolic language. There is a risk for increased passivity or indeed increased challenging

behaviour that might be offset by close attention in the early years to behaviours that may be communicative.

This research highlights the importance of considering an individual's particular needs and abilities when identifying an appropriate educational setting and when monitoring the progress of individuals with multi-sensory disability.

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