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Augmenting the awareness of social communication in a congenitally blind child: A case study

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Abstract

This research project explores the social communication skills of a congenitally blind child, ZD (11;02 years). Studies have shown that congenitally blind children with no cognitive deficits can present with ‘autistic-like’ behaviours such as muted or inappropriate facial expressions, lack of eye contact or mutual gaze and atypical turn taking, skills necessary for successful social interaction. Children with Severe Visual Impairment (SVI) have difficulty accessing the visual communication environments which surround them. This can affect their behaviour, their ability to form friendships and can result in feelings of loneliness, isolation, emotional pain and depression.

The researcher hypothesised that a congenitally blind child’s awareness of social communication could be augmented when informed of the visual communicative information within a specific environment, and that on receiving this information ZD might develop better relationships with her peers, feel less isolated and behave differently within that context. The chosen context was at ZD’s harp ensemble where her mother reported ZD exhibited challenging behaviour and ZD had struggled to form friendships.

The researcher carried out structured interviews with ZD, her mother and the harp ensemble teacher to gain a baseline in ZD’s behaviour, relationships and socio-emotional perceptions of herself in harp ensemble. The mother then co-wrote a Social Story with ZD which informed ZD of the visual social communication which took place within harp ensemble. After this the researcher carried out interviews which explored possible changes in ZD’s behaviour, relationships and socio-emotional self-perceptions.

The researcher’s hypothesis was supported by the data collected from the post-Social Story interviews. The information indicated that ZD’s awareness of social communication skills had been augmented upon the acquisition of visual communicative information that took place within harp ensemble. Results indicated that ZD’s behaviour was less challenging, she formed friendships with her peers and no longer had negative perceptions of herself as she felt included within the group.
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Introduction

The present study is an investigation into the social communication skills of a congenitally blind girl with no cognitive disabilities. ZD (11;02) has a diagnosis of Leber’s Congenital Amaurosis, an autosomal-recessive genetic disorder, in which the rod and cone cells in her retina are undeveloped and do not function. ZD’s vision is limited to some light and dark perception.

Blind children have difficulty with the social aspects of their communication due to their inability to perceive non-verbal visually dependent communication (Botting, 2007). These social interaction difficulties affect their emotional and social well being. Research has shown that some blind children have difficulty making friendships and suffer from feelings of loneliness, emotional pain, isolation and depression (Buuljents et al., 2002, Celeste, 2007 and Roe, 2008). Frustration and challenging behaviour is also commonly reported in blind children because they misunderstand their conversation partners i.e. they are unable to access visual communication, therefore they do not receive the full communicated content (Hoff, 2005).

The researcher hypothesises that if informed of the visual communicative information that takes place within a specific context, will:

- ZD’s behaviour change as a result of feeling less frustrated?
- Changes take place in her relationships with the scenario participants due to her increased awareness of the communication taking place?
- ZD’s socio-emotional self-perceptions alter as friendships are formed and she feels less frustrated?

The overall aims of this project are:

- To ascertain whether ZD’s awareness of social communication is augmented when her mother provides her with the visual social communication within harp ensemble.
- To ascertain whether changes take place within ZD’s behaviour, relationships and socio-emotional self-perceptions when she has been given the visual communicative information that takes place within harp ensemble.
Literature Review

Classification of Visual Impairment

In this research project the researcher refers to blindness and SVI as terms which describe an individual who has no sight other than some light and dark perception.

Communication development in severely visually impaired children

Children with congenital blindness and no cognitive disabilities are typically able to learn spoken language and are able to read and write using systems such as Braille. For a long time it was thought that blindness had no affect on language development (Paul, 2007). There has, however, been vast contrary evidence that a deficiency of the primary sense, sight, affects blind children in all aspects of their development, including their acquisition of language (Warren, 1994).

Pre-linguistic skills such as eye contact, early turn taking (dependent on facial expressions) and triadic gaze cannot be developed and enjoyed by a mother and her severely visually impaired baby (Pereira & Conti-Ramsden, 1999). Children with SVI are more likely to have delayed acquisition of phonemes with highly visible articulation such as /b/, /m/ and /f/ (Mills, 1983). In syntactic development, blind children may be delayed in their acquisition of ‘I’ as a stable pronoun (Fraiberg & Adelson, 1973, Andersen et al. 1984) and auxiliary verbs ‘can’, ‘will’ and ‘do’ (Landau & Gleitman, 1985).

Studies have shown that blind children do not describe characteristics of objects or their locations, therefore showing a great difficulty in describing their external reality (Millar, 1983, Pereira & Conti-Ramsden, 1999). There are also frequent occurrences of underextension in word meanings, where blind children use words with narrower meanings than their adult counterparts (Webster & Roe, 1998).

Blind children may have difficulty determining whether the listener is both present and attending to them, as they are not able to establish mutual gaze. Joint attention, essential for establishing referencing between conversation participants, is delayed in the development of children with SVI (Preisler, 1991).
Studies have found that blind children use gestures to communicate, although less frequently than sighted children and only for nearby objects, where sighted children would use gesture for both nearby and distally located objects (Iverson and Goldin-Meadow 1997, Iverson et al. 2000). Typical communicative gestures, such as pointing requesting or pointing, are absent in blind children (Perez-Pereira & Conti-Ramsden, 1999).

Blind children’s access to non-verbal communication and its context are limited by what can be perceived through senses other than vision (Hoff, 2005). Mills (1993) reports that blind children have a reduced repertoire of non-verbal behaviour, including muted or inappropriate facial expressions, lack of eye contact and a-typical turn taking. She also observed that blind children may ask many questions, sometimes inappropriately, may use echolalia and make comments inappropriate or irrelevant to their context. Research has also shown that blind children do not make reference to actions performed by other people, only themselves, concluding that their speech is egocentric (Anderson et al. 1984, Landau and Gleitman, 1985, Perez-Pereira & Castro, 1992).

Research has shown that blind children develop language skills differently to their sighted peers. Many of the differences in the language development of children with SVI affect the acquisition of pragmatic language skills and socio-communicative difficulties (Tadic et al. 2010).

**Diagnosing social communication difficulties in children with SVI**

Pragmatics is the study of how language is used to communicate within its situational context. Philosopher, Paul Grice, proposed that conversations are governed by an assumption that all conversation participants are co-operating with each other. This ‘Co-operative Principle’ consists of four conversational maxims: ‘Quantity’ – a participant’s contribution should be no more or less informative than required; ‘Quality’ – each participant’s contribution should be truthful; ‘Relation’ – each participant’s contribution should be relevant to the conversation; and ‘Manner’ – each participant’s contribution should be clearly expressed: not vague, ambiguous or excessively wordy (Grice, 1975).
James and Stojanovik (2006) draw similarities between blind children and children with Pragmatic Language Impairment (PLI), who also have social language difficulties. Whilst able to use complex sentences and a large vocabulary, these children have difficulty with functional communication such as turn taking, poor understanding of roles, limited conversation topics, a lack of sensitivity to social cues and a tendency to give too much or too little information. They, therefore, struggle to follow Grice’s four maxims of conversation (Botting, 2007). Children with Autistic Spectrum Disorder (ASD) and Asperger’s Syndrome also have difficulties with pragmatic language and social communication, such as eye contact, joint gestures and facial expressions, which affect their ability to understand and effectively use social skills to interact and communicate with others (Adams et al, 2004).

Individuals with autism also have pragmatic language difficulties (Bishop, 2000). Autistic behaviours have been anecdotally associated with congenital blindness for decades (Volkmar et al, 2005). There have been many clinical reports of autism or ‘autistic-like’ features in children with congenital blindness (Adams et al., 2004, Fraiberg 1977, Rogers & Newhart-Larson, 2008, Hobson & Bishop, 2003, Brown et al. 1997). In their study (2003), Hobson and Bishop observed ‘autistic-like’ qualities in the social interactions, including social engagement, emotional tone, play and language, of congenitally blind children. They made parallels between behaviour exhibited by these children and sighted autistic children. It has been suggested that the condition Leber’s Congenital Amaurosis may have a particular neurological disposition for these similarities (Rogers & Newhart-Larson, 1989).

In a case study of a child with SVI, Kekalis and Sacks (1992) found that their participant’s social communication difficulties were a result of a lack of information about the visual aspects of their interactions. For example, after greeting his peers the child found it difficult to maintain conversations as most of the other children’s interactions were based on, and maintained by, the visual perceptions they shared. Brown et al (1997) suggest this lack of visual experience causes autistic-like behaviour. Their study proposes a diagnosis pragmatic difficulties rather than ASD. Hobson and Bishop (2003) also suggest that it is the environment as experienced by the congenitally blind child that may join with other factors in causing autistic features to develop, rather than a neurological aetiology. Pawletko (2002) believes that there
is inadequate evidence that these autistic-like behaviours are related to the blind child’s sensory impairment. However, her study suggested that children with significant visual impairment, with a neurological vulnerability, can also be on the autistic spectrum. She states that terminology, such as ‘autistic-like’, can result in misdiagnosis and/or delay in appropriate services for a child who is blind and has ASD.

Although there is ongoing debate as to the aetiology of pragmatic language difficulties and socio-communicative difficulties in children with SVI, some research has explored the effects of social communication deficits on a blind child’s socio-emotional development. Socio-emotional development considers how an individual’s social experiences impact their emotional development, including their development of self-esteem, how they form relationships, and develop their identity (Huitt, 2008).

**Socio-emotional development in severely visually impaired children**

Children spend a lot of time with other children, and the quality of these interactions, and the ability to form friendships, greatly affect a child’s quality of life. A number of skills are learned through friendships, including emotional development i.e. emotion regulation, adaptation to stress and management of aggression and conflict, as well as cognitive development i.e. problem solving and knowledge acquisition (Roe, 2008). Friendship forming for blind children is not the natural process experienced by sighted children, but learned through the support of significant others in the child’s life (Sacks & Gaylord-Ross, 2006). Children with SVI also find other skills challenging which are necessary for successful social interactions, for example, internalising standards of conduct and thought, and understanding their role within a wider social system i.e. school (Warren, 1994). As blind children have difficulties accessing and understanding the communicative environment which surrounds them they can often become frustrated and develop behavioural problems (Hoff, 2005).

Wolffe (2006) states that social and emotional development is crucial in the lives of children and young people in order to build friendships and, in the long term, intimate relationships, to avoid loneliness and possible depression. Learning social communication skills is also critical to a child’s inclusion in an education setting (MacCuspie, 2006). Good interpersonal social skills, academic achievement and 8
acceptance from peers are correlated with future success as an adult (Walz and Bleuer, 1992). Sacks & Kekelis (1992) described the blind children that they observed in mainstream schools as isolated, emotionally in pain, lacking the social skills to start and carry on conversations, play games effectively, join in and be part of the group. Huure and Aro (1997) also reported in their study that adolescents with SVI had fewer friends and dates than sighted adolescents, and those with SVI reported feelings of loneliness and difficulty making friends. Self esteem and social skills were lower in girls with SVI than boys with SVI. However, Huure & Aro’s results indicated that frequency of depression and distress in adolescents with VI did not differ from sighted adolescents.

In Britain the social inclusion of blind children in mainstream education has been prioritised behind, and sometimes been obscured by ensuring the child’s access to the curriculum. The success or failure to integrate children with SVI into mainstream schools was often put down to their personality, although many of these children were given no help in their social development (Buuljents et al. 2002).

Current research suggests that there is sufficient evidence that blind children are disadvantaged in developing pragmatic non-verbal language skills; however there is currently little literature on ‘what is to be done about it’ (Carey, 2001 cited by Buuljents et al. 2002). One study by Roe (2008) suggests activities should be carried out with children with SVI to help them develop social communication skills including participating and being included within a group, expressing feelings and understanding the feelings of others’, understanding others’ perspectives, gaining attention, initiating and maintaining conversation, and developing strategies to cope with conflict. Roe suggests children with SVI can learn these through interactions with positive role models and praise for successful social interactions. He states that blind children should have access to an understanding environment and specialist planning in order that they have opportunities to develop self esteem and confidence, whether through group or individual activities. Celeste (2007) also recognised the need to help children with SVI enhance their social communication skills. She developed a ‘Social Skills Intervention Plan’ which consisted of classroom interventions which sought to help the other sighted children in the class include the child with SVI. It also involved
individual sessions teaching social behaviour to the child using role-play in which the child practised how she might interact within her environment.

The above research clearly suggests that children with SVI need help in developing their social communication skills, and offers some advice on working with the child individually or within an inclusive group. Currently, however, there is no exploration of the affects of providing a blind child with the visual communicative information which takes place within their environment. Neither is there a suggested tool, strategy or specific approach for informing blind children of this information.

**Hypothesis**

Research suggests that there is sufficient evidence that congenitally blind children can present with language difficulties, particularly pragmatic language deficits similar to those experienced by children with PLI and ASD. Although researchers have debated whether blind children with these ‘autistic-like’ tendencies should be given a diagnosis of ASD, or should be regarded separately, the difficulties evidenced are grounded in the inability of these children to access visual information necessary to decode non-verbal communication, therefore putting them at a disadvantage when it comes to social and academic participation and peer interaction. Research also shows the effects of socio-communicative difficulties on the socio-emotional development of children with SVI, including difficulty in forming friendships, isolation, loneliness, emotional pain and possibly depression, unsuccessful inclusion at school and therefore risk of underachievement academically.

The researcher hypothesises that a congenitally blind child’s awareness of social communication may be augmented when informed of the visual communicative information that takes place within a specific context. The researcher proposes that on acquiring awareness of this information a blind child’s communication-related frustrated behaviour may decrease. It may also support the child’s development of relationships with the scenario participants and the child’s socio-emotional self-perceptions may positively change as friendships are formed and possible frustration diminishes.
Methodology

Rationale

The researcher chose to carry out an explanatory single case study in order to investigate the unique situation with which ZD presents. Case study research design collects qualitative data - objectively recorded information from observations of a single case - from which interpretations and conclusions are drawn by the researcher (Stake, 1995). Yin (2009) states that the distinguishing characteristic of case study research is that it investigates a contemporary phenomenon in a real-life context.

The researcher considered designing a collective case study research project; however she was unable to obtain permission for the participation of any other congenitally blind child. A significant difficulty in single case study research is its inability to generalise results to other clients (Pring, 2005). However, Warren (1994), a researcher in the development of blind children, describes a preference for individual case study with this client group as there are not enough subjects to create a sample population. For this reason there are a number of publications which study blind children as single case studies (Brambring, 2005, Celeste, 2006, Celeste, 2007).

Procedure

This research project studies the social communication awareness of a congenitally blind girl ZD (11;02). ZD and her family are known to the researcher. It had been identified in a discussion between the researcher and ZD’s mother, AD, that ZD displayed behaviour which her teacher found challenging and failed to make friendships with her peers at her harp ensemble group. AD and the researcher discussed the possibility of this resulting from ZD’s inability to access visual communication between herself and other conversation participants in the environment. AD notified the researcher that she intended to write a Social Story with ZD, which would inform her of the visual communicative information in harp ensemble. The researcher was invited to investigate whether this might augment ZD’s awareness of social communication and help her make friends, create more positive socio-emotional self-perceptions and change her behaviour.
The researcher obtained data through structured interviews with ZD, AD and her harp ensemble teacher, HN, as recommended for data collection in case study research (Tellis, 1997). Interviews took place within the participant’s homes between September and December 2010.

Specific questions were asked around three main areas in which the researcher anticipated change after the Social Story was co-written (see appendices H-J) (Yin, 2009). These areas examined ZD’s behaviour, relationships and socio-emotional perceptions of herself. The pre-Social Story interviews formed a baseline against which change could be measured in the post-Social Story interviews. In order to measure potential change the questions remained consistent in both the pre and post-Social Story interviews, with the exception of an additional post-Social Story question which investigated the process of writing the Social Story.

In order to ensure that the data was not influenced or manipulated by the researcher during the interviews, interview questions were carefully prepared. The questions were created using ‘clean language’ - a communications methodology which helps the interviewee convey their meanings, free of emotional or distracting interpretations from the interviewer (Sullivan & Rees, 2008).

The researcher observed AD and ZD co-writing a Social Story (see appendix N), jointly identified by AD and the researcher as an appropriate method to increase ZD’s awareness of the visually dependent social communication information that took place at harp ensemble. There is no current informative tool or strategy for providing this information to blind children. However, the researcher and AD were both aware of Social Stories which were developed to help children with social communication difficulties, with diagnoses of ASD and Asperger’s Syndrome, access social information (Gray, 1991). The strategy is based on the philosophy that social skills are improved by social understanding (Gray, 1998). Each Social Story is carefully personalised and provides information about the social situations that individuals find difficult and confusing (The Gray Centre, 2010).

The researcher carried out structured interviews with the participants after the Social Story had been written, in order to evaluate whether ZD’s awareness of the social
communication within the scenario had increased, and identify any changes in her behaviour, relationships and socio-emotional self-perceptions.

In order to analyse the results the researcher compiled a case record in which relevant information was arranged chronologically and by topic (Patton, 2002). A pattern-matching process was then used to compare the expected responses for the post-Social Story answers with the actual responses. This provided an opportunity to explore whether the results matched those predicted, and give rival explanations for any responses which deviated from the expected outcomes (Campbell, 1975).

**Ethics - Consent**

The researcher wrote individual information sheets for each participant (see appendices B - D). AD discussed the project with ZD and signed a consent form giving her permission for both her and ZD’s involvement in the project (See appendix E). HN also signed a consent form giving her permission to be involved in the project (See appendix F). The researcher received ethical approval from De Montfort University (September 2010) to carry out this research project.

**Participant’s Welfare**

It was important that ZD did not feel that she was obliged to take part in the project. She was made aware that she could leave the project at any point in the research project. The parent signed a consent form which outlined ZD’s right to withdrawing her participation. AD and HN also had the right to withdraw their participation in the project at any time. This was highlighted to them in the information sheets.

All interviews were recorded to ensure that the data analysed in this project were true accounts of the interviews, and could not be manipulated by the student. Narrative transcriptions of each interview were recorded (see appendices K – L and P - R). DVD recordings of the interviews are submitted separately to the project ensuring participant confidentiality.

**Confidentiality**

ZD’s parent and harp teacher were informed that no identifying information will be revealed in this research project.
Discussion and Analysis of Data

Data Presentation

The qualitative data collected in the three pre-Social Story interviews has been compiled into Table i (see appendix G). This provides baseline results of ZD, AD and HN’s responses describing ZD’s behaviour, social relationships and socio-emotional perceptions of herself before ZD was informed of the visual social communication information which took place within harp ensemble.

The data collected in structured interviews with the participants, post Social Story, is compiled in Table ii (see appendix L). This table shows both the expected changes in responses describing ZD’s behaviour, social relationships and socio-emotional self-perceptions, and the actual responses.

Discussion of Baseline data

This discussion is arranged under the themes of ZD’s behaviour, relationships and socio-emotional perceptions of herself, in which the researcher expected change once ZD was informed of the visual social communication which surrounded her at harp ensemble. This information was obtained through analysis of the responses to the interview questions (see Tables i and ii).

ZD’s Behaviour in Harp Ensemble Pre-Social Story

HN describes ZD’s behaviour as ‘possibly attention seeking’ (appendix M: lines 53-54 [M:53-54]), including behaviours such as ‘huffing and puffing’(M: 22). HN reports that ZD displays these behaviours when she has been corrected or has ‘taken things the wrong way’ (M:40-41). AD similarly reports that ZD displays behaviours such as crying, making her body rigid, holding her breath, being ‘cheeky’ and being ‘stroppy’(L:81-86) which she describes are a result of frustration and misinterpreting HN’s comments, such as reacting to criticism or interpreting HN speaking in a loud voice as aggressive, rather than because HN naturally has a loud voice. AD describes feeling in the middle of both HN and ZD, observing how they misinterpret each other: HN misinterprets ZD’s behaviour, and ZD misinterprets HN’s teaching. ZD also refers to always feeling that she is wrong or making mistakes. She reports
that HN does not say her name when addressing the group; therefore ZD assumes that HN is always speaking to her, even when she is speaking to other children.

ZD does not refer to her own behaviour although does comment that ‘I try to keep these things in’ (K:48). She reports that people at harp ensemble expect her to put up with being treated as if she doesn’t belong to the group.

The researcher anticipated such responses from HN, AD and ZD. Previous literature has found that children with SVI can display challenging behaviour. AD and HN both describe that ZD’s behaviour is a result of misinterpreting her teacher’s teaching style and understanding her to be negative and critical. ZD feels frustrated at getting things wrong or being criticised. This supports literature which reports that blind children exhibit challenging behaviour as a result of difficulties accessing and understanding their communicative environment (Hoff, 2005).

**ZD’s Social Relationships in Harp Ensemble Pre-Social Story**

HN describes her relationship with ZD as challenging but also good and positive. However, AD reports that it is not an easy relationship and ZD finds it hard to relax around HN. ZD reports that HN thinks better of the other girls than herself because she is visually impaired.

HN reports that ZD has good relationships with the other children in her group. AD also describes ZD having friendly relationships with the other children, which are positive as a result of the other children’s parents encouraging relationships with ZD. AD reports that the other girls do not understand some of ZD’s behaviours, i.e. crying, and although they are gradually becoming less ‘scared’ (L: 127) of ZD, some are still ‘shy’ (L: 163) with her because they don’t know how to interact with someone who cannot see them.

ZD describes her relationships with the other girls as a ‘nightmare’ (K:36). She reports that the girls see her as a ‘monster’ (K:37), ‘an alien’ (K:37) and ‘something scary that no one wants to talk to’ (K:40). She reports the girls do not do anything bad to her, but they just talk among themselves: ‘whoever’s there just talk to each other they’d never think of talking to blindy in the corner would they?’ (K:65-66).
ZD’s perceptions of the relationships with her peers are very different from AD and HN’s, although AD reports some difficulties with the other girls being scared to interact with ZD. She reports that some of these difficulties stem from some of ZD’s behaviours. This is an example of how a child with SVI struggles with and needs significant help forming friendships (Huure & Aro, 1997, Sacks & Gaylord-Ross, 2006). It also demonstrates that ZD’s anti-social behaviours and difficulties in forming friendships are inter-dependent: her peers do not understand her behaviour; this scares them so they exclude or ignore her.

**ZD’s Socio-Emotional Self-Perceptions in Harp Ensemble Pre-Social Story**

ZD refers to herself as ‘blindy’ (K:66), ‘monster’ (K:37), ‘alien’ (K:37) and ‘scary’ (K:40), therefore she has developed very negative perceptions of herself in harp ensemble. She describes not knowing what is happening around her, not belonging, not being included in friendships and being criticised by her teacher. AD also reports that ZD can get upset when feeling that she’s not met a standard which HN expects, and describes negative behaviours which take place as a result of frustration and misinterpreting HN’s comments or instructions. As in previous research, ZD, like other children with SVI, feels isolated, lonely, frustrated and is obviously in emotional pain that she cannot join in the group to the same extent as the other children (Sacks & Kekelis, 1992).

AD reports that ZD wants to be independent but has to be dependent on the other girls for mobility at harp ensemble. Although ZD does not refer to this, it will affect her self-esteem as only she has to depend on those around her. Sacks and Gaylord-Ross (1992) state that when children with SVI are helped to be more socially aware they have an increased sense of independence and empowerment.

AD and HN both report that ZD enjoys harp ensemble and gets a lot out of the experience. However, ZD describes it as shockingly bad. ZD’s responses are consistently more negative than both AD and HN’s responses to questions around ZD’s behaviour, relationships and socio-emotional self-perception. The researcher concludes that AD is not aware of the extent of negative feeling ZD attaches to her experience at harp ensemble. Research has shown the negative affects of isolation, loneliness and exclusion on the socio-emotional development of blind children (Sacks, 1992).
& Kekalis, 1992, Huure & Aro, 1997, Sacks & Gaylord-Ross, 2006). Literature is available to parents on how best to support and advocate for education and mobility services to help their developing child with SVI (Zebelski & LaVenture, 2007). Research has also explored the necessity of teaching parents of their critical role in helping their blind infant develop social routines in order to create attachment and communication between them (Urwin, 1983, Moore, 1984). However, there is little information written for parents on the vulnerability of their developing, older child with SVI acquiring negative socio-emotional perceptions of their self as a result of their inability to socially interact within their environments. Other parents, like AD, may also be unaware of the impact of loneliness and frustration on their blind child’s socio-emotional development.

**Model of ZD Pre-Social Story**

This model shows how severe visual impairment and lack of access to visual communication impacts ZD’s social communication development. The three areas of behaviour, relationships and socio-emotional self-perceptions each overlap and influence one another. This results in social interactions being even more difficult for ZD.
Discussion of Post Social Story Data

*Augmenting ZD’s Awareness of Social Communication in Harp Ensemble*

ZD co-wrote a Social Story with her mother which informed her of a variety of visual communication which took place within harp ensemble (see appendix N). ZD states that she had ‘quite a few things were highlighted’ (P:5) to her and particularly remembers advice on her peers’ use of eye contact to understand who is within their conversation. AD also reported surprise at ZD’s unawareness of some communication which AD states she ‘takes for granted’ i.e. understanding people are pleased to see her when they smile at her (Q:14-21). These responses support this study’s first aim: to ascertain that ZD’s awareness of visual social communication has been augmented by informing her of the visual social communication which takes place in harp ensemble.
ZD’s Behaviour in Harp Ensemble Post-Social Story

AD and HN both report a positive change in ZD’s behaviour since ZD was informed of the visual communication taking place within harp ensemble. HN reports that ZD now accepts situations rather than becoming frustrated, and therefore does not behave negatively as a result of her diminished frustration. ZD also reports a positive change: ‘I try to get on with things the much as I can’ (P:83). She laughingly describes a circumstance where she might still be persuaded to misbehave with the other children within harp ensemble but does not refer to any behaviours as reported before the social story, such as crying or being cheeky.

The researcher anticipated these results in her hypothesis. ZD no longer misinterprets comments made by HN and understands the positive visual communication which HN conveys through smiling at ZD. ZD, therefore, no longer feels frustrated and previous behaviours that HN found challenging no longer occur.

ZD’s Social Relationships in Harp Ensemble Post-Social Story

ZD describes making relationships with the other girls as ‘getting easier’ (P:53) and has been invited to join conversations and activities with the girls both within harp ensemble and outside of harp ensemble. AD reports that ZD is being included in conversations and activities separate from the parents. She reports that ZD now understands that the other girls are being friendly with her, and that she has friends at harp ensemble. HN has also noticed that ZD has become friendly with a particular girl in the group.

ZD has made positive comments about HN. She demonstrates that she now understands that HN asks ZD and the other girls to modify their playing in order that the ensemble sounds better. HN and AD both state that HN has a positive relationship with ZD.

These results were expected by the researcher. With reduced challenging behaviour, resulting from reduced frustration, and with the awareness of how her peers use visual communication, the researcher hypothesised that ZD would find it easier to form relationships. This evidence supports the hypothesis that ZD has been able to
form friendships as a result of increased awareness in visual social communication in harp ensemble.

**ZD’s Socio-Emotional Self-Perceptions in Harp Ensemble Post-Social Story**

In ZD’s post-Social Story responses she no longer refers to herself with negative labels, and instead states she now feels she is ‘respected for what [she’s] worth’(P:102). ZD and AD both describe that ZD feels less alienated and more included in the group. ZD also states that the harp ensemble has been ‘really enjoyable’ (P:88) over the last week or two. This is a great difference from ‘shockingly bad’ (K:58) as ZD described harp ensemble before the social story.

These results support the research hypothesis that ZD’s socio-emotional perceptions of herself might alter when informed of the visual social communication within harp ensemble. The researcher suggests that when ZD was enabled to form friendships and understand the communication that she had missed through her inability to access the visual communication, her frustration reduced and so, therefore, did her challenging behaviour. As she was included by her teacher and peers, ZD felt included within the group rather than isolated. She had friends, where previously she was lonely. ZD no longer refers to herself negatively as she has acquired positive socio-emotional perceptions of herself within harp ensemble because she has friends and is no longer frustrated.

**Model of ZD Post-Social Story**

The student anticipated that when understanding the harp ensemble context fully i.e. including the visual social communication, ZD would present with less challenging behaviour, make friends more easily, and have more positive socio-emotional perceptions of herself. The pre-Social Story model (i) of ZD demonstrates that behaviour, relationships and socio-emotional self-perceptions, three factors which are key in acquiring and portraying social communication skills, each impact one another. Now that ZD was been provided with information about the visual communication taking place within harp ensemble the areas continue to impact each other, but positively rather than negatively: reduced challenging behaviour = increased
friendships = increased self esteem = further reduced behaviour = better friendships = less isolation = more included = happier etc. The model interacts positively.

These results support this study’s second aim: to ascertain whether changes have taken place within ZD’s behaviour, relationships with her teacher and peers, and she has developed different socio-emotional perceptions of herself. Increasing ZD’s awareness of the visual social communication that takes place in harp ensemble has ultimately enabled ZD to change the perceptions of how she understands herself within a social network, and therefore her social identity. This interactive model works towards enabling ZD to have a positive identity.

**Model ii: ZD with visual social communication awareness at harp ensemble**

**Other Observations from Post-Social Story Data**

AD reports that since co-writing the Social Story a lot of positive changes have taken place in ZD regulating and monitoring her social skills in contexts other than harp ensemble. AD views this as a positive thing. She also describes the Social Story as
giving her the opportunity to see that ZD had not learned skills that AD had taken for
granted that ZD had acquired, for example not knowing that people smiled at her
when meeting her. This has made her think about other situations where contexts rely
on visual communication, what ZD might be missing or misunderstanding, and how it
may be affecting her. The researcher had not anticipated that the mother should be
so unaware of her child’s lack of awareness of visual social communication. The
researcher has been unable to find any literature with information for parents on the
socio-emotional development of their older blind child. The researcher would suggest
that this area requires further research in order that parents can benefit from
guidance in working with and understanding their developing blind child.

AD described that ZD, although knowing inside that she was different from the other
sighted children in harp ensemble, had been sad at hearing what she was missing
when discussing and writing the Social Story. She was also upset on realising how
disadvantaged she was compared to her peers who naturally joined in the group and
created relationships, rather than requiring help to do so. ZD described the
experience as ‘distressing’ (P:4). This was not expected by either the researcher or
AD and requires further exploration into whether the social benefits of the Social
Story experience are outweighed by the distress of being informed of her disabilities
in detail.

Serious consideration should be given to when a child should be introduced to the
idea that they are different, and how this information should be presented to them.
However, ZD reports that the social story showed her ‘where to go on from here’, and
describes many positive consequences of the social story input. AD states that she
would like to make more social stories with ZD although feels that this should take
place over time in order that ZD does not become too anxious about her social
communication skills.

Harrison and Crow (1993) suggest that parents should discuss visual impairment and
its affects, with their child with SVI. The child is likely to react to this information with
some sense of loss, although with help from parents and adults to nurture feelings of
self worth and a positive self attitude, the experience of discussing disability honestly
should not be traumatic. The researcher has been unable to find evidence which
explores appropriate times and ways to talk to older blind children and adolescents about their disability, and would recommend further investigation within this area before preparing a full-scale study.
Conclusion

The researcher hypothesised that informing a blind child of the visual social communicative information within a specific scenario could augment their awareness of the social communication within that setting. The researcher predicted that with this heightened awareness there might be change in the child’s frustrated behaviour, change in the child’s socio-emotional self-perceptions, and change in the relationships between the scenario’s participants and the child.

Data from the base line interviews with ZD, AD and HN correlated with previous research on the behaviour, relationships and socio-emotional development of blind children. ZD’s experiences at harp ensemble were negative portrayed: isolating, lonely, and frustrating due to ZD’s behaviour, which in turn resulted from misinterpretations of communications with her teacher. ZD’s behaviour, and lack of awareness of the visual social communication around her, meant that forming relationships with the girls around her was difficult. The researcher found that ZD’s behaviour, poor relationships and negative socio-emotional perceptions of herself and her environment, three key factors in acquiring and portraying social communication skills, were inter-related and influenced each other to create an overall negative social context at harp ensemble for ZD.

The post-Social Story results supported the researcher’s hypotheses. Responses from ZD and AD both reported that ZD had become awareness of social communication with harp ensemble had been augmented. And, when given information on the visual social communication that took place within harp ensemble, ZD, AD and HN all described positive changes in ZD, including reduced challenging behaviour, friendships, and a happier disposition towards harp ensemble and ZD’s self. ZD’s now positive behaviour, new friendships, and newly positive socio-emotional perceptions of herself each interact to enforce the new positive experience of harp ensemble for ZD.

The researcher had not expected AD to express surprise at the extent of visual social communication information that ZD had not been aware of before co-writing the Social Story. Nor had the researcher anticipated that AD would not be aware of the extent of negative self-perceptions and experiences that ZD reported in her pre-
Social Story interview. Research exists which states the risk of negative socio-emotional development in blind children. However, currently little or no information is accessible to parents informing them of the impact of negative socio-emotional development on their child with SVI i.e. depression, isolation etc. The researcher would suggest further research needs to be undertaken to make this information more accessible to parents.

ZD and AD both reported ZD’s distress at discussing her disability and how she differed from other children in the harp ensemble context. The researcher would suggest further research in the areas of counselling approaches for children with SVI, so that the parent or person informing a child with SVI of their differences to sighted children is equipped to support the child if they experience similar distress or upset. Research could also explore a suggested age at which it would be appropriate to discuss these differences and difficulties with children with SVI. In this research both AD and ZD maintained that this was a positive experience. Therefore the researcher might hypothesise that, despite the initial upset of discussing ZD’s differences, the overall outcome was sufficiently positive for it to be worth the discomfort.
Description of Full Scale Study

Ethical Issues

Before commencing a full scale study the researcher should consider the emotional implications of informing a blind child of their differences to of a sighted child. This may include investigating what age a child can accept that they are different from a sighted person.

Size of Sample

This pilot study is limited by the fact that it is a single case study (Pring, 2005). The researcher was aware of this at the outset of her research, however, there is not a large population of children with SVI without cognitive impairments. The researcher was unable to get permission from any other such candidates to take part in her study. The results cannot, therefore, be generalised to other children with SVI.

A full scale study could be carried out with more than one child by a professional who worked with a number of children with SVI, for example within a specialist school. Within this setting it would be possible to carry out a full scale study could and compare a collection of case studies.

Research Statement

The research statement ‘Augmenting the awareness of social communication in a congenitally blind child: a case study’ is appropriate for the pilot study. For a full scale with a larger number of participants the research statement might change to ‘Augmenting the awareness of social communication in congenitally blind children’.

Methodology

The full scale study would be a multiple case study. The researcher would use the same methodology procedure as that in the above pilot study but would additionally compare the results of the participants.
Data and Analysis

The data would be collected using recorded interviews, as in the pilot study. The data would initially be analysed as it has been in the pilot study. The researcher would use the individual analyses to generate as many implications of the hypotheses as possible (Levy, 2005).

Results

A full scale study, as a multiple case study, would show whether current research is accurate in stating that blind children have communication related frustrated behaviour, have difficulties in forming relationships and suffer from negative socio-emotional perceptions of their selves. The study would investigate whether the awareness of visual social communication is augmented in all of the participants, and if not, analyse possible reasons as to the varying outcomes.

A full scale study would ascertain if heightened awareness of visual social communication changes the behaviour, relationships and socio-emotional self-perceptions of all, some or none of the sample of blind children and investigate possible reasons should the results differ.

Finally, a full scale study would show whether the results of the single case study, which support the researcher’s hypotheses, can be generalised to a small population of blind children. The researcher believes that current literature and the results of the single case study support the hypothesis that blind children’s social communication awareness can be augmented and legitimises the consideration of a full scale study.
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Appendix A

References


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Appendix B

Information Sheet: ZD

(Original Format: Braille)

Dear ZD,

Thank you for your interest in being involved in my Research Project.

I would like to come and talk to you about your communication, and how you feel during your harp ensemble. I will bring a video camera and record our session. I shall also be talking to your mum and your harp teacher about these issues.

You and your Mum will then write a story about all the communication that happens during harp ensemble.

After we have written the story I would like to talk to you, your mum and your harp teacher to see if you feel and behave any differently in harp ensemble after writing the story. I will be writing about these feelings and observations (things that were seen) in my research project.

It is absolutely fine if you have changed your mind about being involved. You can tell your mum and she will tell me. If at any time you want to stop being involved you can also tell your mum and she will tell me.

When I would like to see you I will make an appointment to come to your house. When discussing the project we will be recorded on video camera.

Yours sincerely,

A A

Speech and Language Therapy Student
Appendix C

Information Sheet: AD

Dear AD,

Below is some information about my research project: ‘Augmenting the awareness of social communication in a congenitally blind child: A case study’.

Background to Project

Current research shows that having a congenital severe visual impairment affects a child’s development of language, particularly non-verbal communication dependent on eye contact (their pragmatic language skills). This may affect the child’s acquisition of social communication skills, and may have an impact on their social participation and peer interaction.

My hypothesis is that when informed of the missing visual communication, a blind child’s understanding of social communication will be augmented and there may be changes in (a) their behaviour (less frustrated) and (b) the development of their relationships with the conversation participants, i.e. peers.

Method

Initially I would like to carry out structured interviews with yourself and ZD to discuss ZD’s communication in a specific, identified scenario where it has been identified that she is missing out on key information communicated through eye contact. Then, as discussed, the strategy we will use to inform ZD about the extra missing communication is a Social Story.

I will observe you co-writing and recording a Social Story about this scenario with ZD.

After you have recorded this story I would like to find out if it makes her feel different in that scenario, and if so, how and why. I would also like to ask you, ZD and her harp teacher if you notice any changes during the scenario after writing the Social Story.

Project Aims

The overall aims of this project are:

(1) To find out if you and ZD feel she has any communication difficulties as result of her visual impairment

(2) To ascertain the extent to which ZD has insight into these potential difficulties

(3) To see if ZD, you and her harp teacher identify any changes in ZD when we augment ZD’s understanding of expectations and social protocol, dependent on visual communication within a specific scenario.
ZD’s Welfare

It is important that ZD makes the decision whether or not she is happy to be involved in the project, and, as volunteers to participate in this project, you are both able to withdraw your permission to participate at any time. If ZD should become upset during the project I shall understand that as a valid refusal.

Any information that is recorded will be strictly confidential. It will only be accessed by myself, my supervisor and possibly the person who marks my dissertation. No information will be written that could identify ZD or yourself.

If you have any other questions you are welcome to contact me,

Yours Sincerely,

A A

Speech and Language Therapy Student
Appendix D

Information Sheet: HN

Dear HN,

It has been identified by the parent of ZD that she feels, due to her inability to access visual communicative information (i.e. eye contact, gestures etc.), that ZD struggles to understand some social situations which might affect her behaviour and emotions.

I am carrying out a research project which studies the affect of augmenting a blind child’s communication in a specific social scenario. The parent suggested using harp ensemble as a scenario.

Below is some information about my research project: ‘Augmenting the awareness of social communication in a congenitally blind child: A case study’.

Background to Project

Current research shows that having a congenital severe visual impairment affects a child’s development of language, particularly non-verbal communication dependent on eye contact (their pragmatic language skills). This may affect the child’s acquisition of social communication skills, and may have an impact on their social participation and peer interaction.

My hypothesis is that when informed of the missing visual communication, a blind child’s understanding of social communication will be augmented and there may be changes in (a) their behaviour (less frustrated) and (b) the development of their relationships with the conversation participants, i.e. peers.

Method

Having identified with ZD the possible visual communication that she misses out on whilst at your harp ensemble I would like to come and observe a session and see ZD in this scenario. Afterwards I would like to carry out an interview with you to discuss if you feel there were any changes in ZD’s behaviour and demeanour throughout the session.

Project Aims

The overall aims of this project are:

(1) To find out if ZD feel she has any communication difficulties as result of her visual impairment

(2) To ascertain the extent to which ZD has insight into these potential difficulties

(3) To see if ZD, her parent and you identify any changes in ZD when we augment ZD’s understanding of expectations and social protocol, dependent on visual communication within a specific scenario.
As a volunteer to participate in this project, you are able to withdraw your permission to participate at any time. Any information that is recorded will be strictly confidential. It will only be accessed by myself, my supervisor and possibly the person who marks my dissertation. No information will be written that could identify you.

If you have any other questions you are welcome to contact me,

Yours Sincerely,

A A

Speech and Language Therapy Student
Appendix E

Consent Form: ZD & AD

Project Title: Augmenting the awareness of social communication in a congenitally blind child: a case study

Investigators

P C, Division of Speech and Language Therapy, Faculty of Health and Life Sciences
Hawthorn Building
Leicester
LE1 9BH

A A, Division of Speech and Language Therapy, Faculty of Health and Life Sciences
Hawthorn Building
The Gateway
Leicester
LE1 9BH

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my and my daughter’s participation is voluntary and that we are free to withdraw at any time, without giving any reason.

3. I understand that my daughter and I will be videoed/audio taped/interviewed and give permission for the student and her university supervisor to analyse the video/audio tape.

4. I understand that the results may be published but that confidentiality will be maintained throughout and I and my daughter will not be referred to by name or any identifying information.

5. I agree to take part in the above study.

6. I agree for my daughter to take part in the above study.

Name of Participant             Date    Signature
Name of Researcher             Date    Signature

P07227341  SALT 3201  ‘Augmenting the awareness of social communication in a congenitally blind child: A case study’
Appendix F

Consent Form HN

Project Title: Augmenting the awareness of social communication in a congenitally blind child: A case study

Investigators

P C, Division of Speech and Language Therapy, Faculty of Health and Life Sciences Hawthorn Building The Gateway Leicester LE1 9BH

A A, Division of Speech and Language Therapy, Faculty of Health and Life Sciences Hawthorn Building The Gateway Leicester LE1 9BH

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that I will be videoed/audio taped/interviewed and give permission for the student and her university supervisor to analyse the video/audio tape.

4. I understand that the results may be published but that confidentiality will be maintained throughout and I will not be referred to by name or any identifying information.

5. I agree to take part in the above study

Name of Participant Date Signature

Name of Researcher Date Signature

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### Table i: Pre Social Story Data (Baseline)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Response ZD</th>
<th>Response AD</th>
<th>Response HN</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Perceptions of harp ensemble</td>
<td>‘No one respects me there’</td>
<td>A group that ZD attends Children aged roughly between 7:06 and 12:00</td>
<td>A group of HN’s best, most committed, most technically able students Aim of the group is to compete in competitions</td>
</tr>
<tr>
<td></td>
<td>‘No one talks to me, I always get left behind’</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘[I] sit there not knowing what’s going on’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. ZD’s relationship with HN</td>
<td>‘She moves me on too fast’</td>
<td>‘[ZD] finds it hard to relax around HN’</td>
<td>Positive, good relationship but can be challenging: back chat, huffing and puffing ‘Have to be on the ball all the time’ ‘Generally I let it go rather than rising to the occasion’</td>
</tr>
<tr>
<td></td>
<td>[HN] thinks the other girls are more special than me because I’m blind...they’re better players and they’ve got more talent than me’</td>
<td>‘HN asks for more from ZD even after she has been practising hard, ZD gets upset as she doesn’t feel she’s giving HN what she wants ‘Not an easy relationship’ HN misinterprets ZD’s behaviour and ZD misunderstands HN’s actions</td>
<td></td>
</tr>
<tr>
<td>3. ZD’s understanding of HN’s communication</td>
<td>ZD unable to distinguish who HN is talking to as HN does not use her name: ZD assumes HN is always talking to her, therefore, correcting her ‘She tells the other kids what I don’t know’</td>
<td>AD feels ZD misinterprets HN’s teaching style as impolite, criticising and interrupting Can get frustrated as a result of this resulting in a variety of behaviours (see question 7).</td>
<td>‘Normally very good’ ‘I try to make sure I don’t say anything I don’t mean’ – keeps communication unambiguous HN believes ZD can take positive comments the wrong way</td>
</tr>
<tr>
<td>4. ZD’s relationships with other children in harp ensemble</td>
<td>‘A nightmare’ ‘People think I’m a total monster...an alien’ ‘I don’t belong there’ ZD perceives herself as something no one wants to talk to</td>
<td>Friendly relationships Parents of other children are really positive with ZD and children are starting to copy their parents ZD experimenting with friendships Other girls don’t understand some of</td>
<td>‘[ZD] has good relationships with everybody’</td>
</tr>
</tbody>
</table>

Appendix G
<table>
<thead>
<tr>
<th>5. Perceived differences between ZD and other group members</th>
<th>(not asked question)</th>
<th>ZD needs more time to listen to what’s happening before participating. ZD more dependent on help from other children and does not like being dependent.</th>
<th>More musically advanced than other children in her group.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>6. ZD’s understanding of environment at harp ensemble</strong></td>
<td>‘Everything is my fault’: ZD feels blamed all the time by HN</td>
<td>(not asked question)</td>
<td>(not asked question)</td>
</tr>
<tr>
<td><strong>7. ZD’s behaviour at harp ensemble</strong></td>
<td>‘I try to keep these things in’ ZD thinks people at harp ensemble expect her to put up with being treated as if she doesn’t belong in the group.</td>
<td>Shows unusual behaviour due to misinterpreting HN when correcting ZD or other child but not using names so ZD assumes HN is talking to her. Behaviours include crying, being stroppy, being cheeky, ‘letting her mouth go’, making her arms and legs rigid and holding her breath to stop herself crying.</td>
<td>‘Possibly attention seeking behaviour’ ZD has false perception that HN criticises her when she is correcting her Huffing, puffing, teenagery behaviour: could be due to not seeing the cause of HN’s decisions i.e. repeating practise of parts of music.</td>
</tr>
<tr>
<td><strong>8. ZD’s overall enjoyment of harp ensemble</strong></td>
<td>‘Even less than shockingly bad’ ZD feels the other girls aren’t bad, they just don’t include her and she feels left out. ‘They’d never think of talking to blindy would they?’</td>
<td>Likes harp ensemble – it gives ZD sense of being part of a group. Enjoys performing and feeling special</td>
<td>ZD really enjoys harp ensemble, gets a lot out of it.</td>
</tr>
</tbody>
</table>
Appendix H

Interview Questions: ZD

1) Harp ensemble, what is that like?
2) Your teacher HN, what is she like?
3) Your understanding of what HN says, what is that like?
4) Making friends at harp ensemble, what is that like?
5) Your understanding of everything that happens around you at harp ensemble, what is that like?
6) Your behaviour at harp ensemble, what is that like?
7) Your enjoyment at harp ensemble, what is that like?

Clean language questions to follow on from ZD’s answers (metaphor statements/everyday statements) to above questions:

Developing Questions

- (And) what kind of...is that like?
- (And) where is...?
- (And) that’s like what..?

Sequence and Source Questions

- (And) then what happens?

Intention Questions

- (And) what would ... like to have happen?"
- (And) what needs to happen for...?"
- (And) can ... happen?"

Additional Post Social Story Interview question

1) Making the social story, what was that like?
Appendix I

Interview Questions: AD

1) Harp ensemble, what is that?
2) ZD’s relationship with her teacher, what’s that like?
3) Zoe’s understanding of what her teacher says, what’s that like? Regarding ZD doing what her teacher says/asks, what’s that like?
4) ZD’s behaviour at harp ensemble, what’s that like?
5) ZD’s relationships with the other children at harp ensemble, what are they like?
6) Are there differences between ZD and the other children at harp ensemble?
7) The differences between ZD and the other children at harp ensemble, what are they?
8) ZD’s enjoyment of harp ensemble, what is that like?

Clean language questions to follow on from AD’s answers (metaphor statements/everyday statements) to above questions:

Developing Questions

• (And) what kind of...is that like?
• (And) where is...?
• (And) that’s like what..?

Sequence and Source Questions

• (And) then what happens?

Intention Questions

• (And) what would ... like to have happen?”
• (And) what needs to happen for...?”
• (And) can ... happen?”

Additional Post Social Story Interview question

1) Making the social story, what was that like?
Appendix J

Interview Questions: HN

1) Harp ensemble, what is that?
2) Your relationship with ZD, what’s that like?
3) ZD’s understanding of what you say, what’s that like? Regarding ZD doing what you say/ask, what’s that like?
4) ZD’s behaviour at harp ensemble, what’s that like?
5) ZD’s relationships with the other children at harp ensemble, what are they like?
6) Are there differences between ZD and the other children at harp ensemble?
7) The differences between ZD and the other children at harp ensemble, what are they?
8) ZD’s enjoyment of harp ensemble, what is that like?

Clean language questions to follow on from HN’s answers (metaphor statements/everyday statements) to above questions:

Developing Questions

• (And) what kind of...is that like?
• (And) where is...?
• (And) that’s like what..?

Sequence and Source Questions

• (And) then what happens?

Intention Questions

• (And) what would ... like to have happen?“
• (And) what needs to happen for...?“
• (And) can ... happen?”

No Additional Post Social Story Interview questions
Appendix K

Pre-Social Story Interview ZD

1. Student: OK so ZD can you tell me harp ensemble what is that like?
2. ZD: oh it’s just like really weird in a way because it’s just like no one really respects me there
3. Student: respect what kind of respect is that like?
4. ZD: like talks to me or anything I’m the one who always gets left behind
5. Student: left behind like what?
6. ZD: because they’ve all got DSs and stuff and I’ve not even got one yet and then they all start talking about the latest cooking mama and I’m like (moves lips) sitting there not knowing what’s going on
7. Student: is there anything else you’d like to tell me about harp ensemble?
8. ZD: well the girls are OK when they actually talk to me but they just talk really posh to me I just wish they’d be normal
9. Student: OK and your teacher HN what is she like?
10. ZD: she moves me on too fast like yeah
11. Student: that’s like what?
12. ZD: because I’d just done my grade 3 in December 2009 and then she quickly moved me onto grade 4 stuff
13. Student: and what about in harp ensemble what is your teacher like?
14. ZD: well she thinks of the other four well the other girls in the group as more special and better than me just because I’m blind
15. Student: what kind of special is that like?
16. ZD: they’re better players and they’ve got more talent than me
17. Student: OK and what about your understanding of what HN says what is that like?
18. ZD: well she doesn’t say who she’s talking to so I always think it’s me all the time that’s going wrong and when they say harp one and harp two practise together I know where that’s where I’ve gone wrong and I’m really unhappy about it
28. because I think of the harp threes and one of them’s only been playing for three months all them are better than me

30. Student: ok anything else about your understanding of what HN says?

31. ZD: it never really you know like it’s quite hard to say but she sort of tells the other kids what I don’t know and says (high pitched voice) oh no you weren’t here in the ensemble that I said that and really she was telling them in lessons I suppose

35. Student: OK and making friends at harp ensemble what is that like?

36. ZD: oh a nightmare I think the best way to describe myself there is that people think I’m a total monster or an alien I don’t believe I don’t belong there rather like there inhabitants and I’m just an extra terrestrial thing floating about with them

39. Student: (laughs) a monster what kind of a monster is that like?

40. ZD: just something scary that no one wants to talk to or something disgusting

41. Student: and what about your understanding of everything that happens around you at harp ensemble what’s that like?

43. ZD: everything is my fault it seems like I was saying a minute ago it’s just seems never to be them and always to be me everyone seems to be blaming me all the time because they always say (puts on high voice) oh harp one could you just do that again or something like that

47. Student: what about your behaviour at harp ensemble what’s that like?

48. ZD: I try to keep all these things in and pretend to go along with them like normal because people expect me to be like that just to think that it’s ok for them to treat me like that

51. Student: like that what kind of like that is that?

52. ZD: you know what I was saying about being extraterrestrial

53. Student: OK so just tell me again what do you mean what kind of extraterrestrial is that like?

55. ZD: it just seems like I don’t belong there

56. Student: and finally what about your enjoyment of harp ensemble what is that like?

58. ZD: on a scale from one to ten when shockingly bad is one and ten is good really, really good it’ll probably be zero that’s even less than shockingly bad
60. Student: oh ok shockingly bad what’s that like?

61. ZD: oh it's just cos everyone else seems to get along with everyone else and then there’s me sitting there at my harp like being neglected as such out of the and they don’t exactly do anything bad it’s just they don’t do really anything very much they just talk to themselves well not talking to themselves obviously but the other three or whoever’s there just talk to each other they’d never think of talking to blindy in the corner would they?

67. Student: OK well that’s all my questions do you want to finish there or is there anything else you’d like to tell me about harp ensemble?

69. ZD: let's leave it there

70. Student: OK thanks very much
Appendix L

Pre-Social Story Interview: AD

1. Student: OK harp ensemble what is that?

2. AD: harp ensemble is a group that my daughter ZD attends she plays the harp
3. she’s been playing for a few years now and there are two harp ensembles the one
4. that she goes to is junior harp ensemble which is for children say roughly between
5. the ages of say seven and a half and twelve

6. Student: OK and ZD’s relationship with her teacher at harp ensemble what’s that
7. like?

8. AD: at harp ensemble and or at is that also to do with her class? Her relationship
9. with her teacher [while she attends]

10. Student: [yeah if we think about it in harp ensemble] because we’ll look at it in
11. that scenario it probably will link in but if we just think about it at harp ensemble

12. AD: [yeah ok, yeah right at harp ensemble]

13. AD: OK ZD enjoys the fact that she’s part of a group but struggles to be part of a
14. group she likes the camaraderie when she can join in part of her struggle with
15. the group is understanding some of the nonverbal stuff that goes on and
16. understanding when a teacher’s teaching them and saying something negative
17. maybe like oh you didn’t play that very well or you didn’t get the timing right or
18. can you play a bit louder or quieter ZD reads that as criticism so it’s difficult for
19. her sometimes to keep a lid on her frustration or her tears sometimes she’s cried
20. because she’s misunderstood what is just a general observational part of the
21. teaching the teacher speaks quite loudly because she’s been trained as a singer
22. so she just naturally projects her voice and so I think Zoe interprets that
23. sometimes as more aggressive than it is than she is

24. Student: OK so is there anything else about the relationship this frustration and
25. the things that you’ve told me that she does what is the link between that and the
26. relationship with HN?

27. AD: well I think it’s partly the relationship that she has with HN but it’s all tied up
28. with ZD’s *sighs* ZD’s also quite perfectionist in what she does she loves to do
29. well and she feels like if she’s not doing what she’s been asked to do she can get
30. very upset very frustrated so there’s a bit of a mix of things that’s going on but in
31. general I think she finds it hard to relax with HN because she wants to do her
32. best for HN and give her best and have her best be recognised but HN might
33. very well ask for more she might say do this or you want to do the other play it
34. louder play it softer or whatever and then ZD gets quite upset because she feels
she’s not giving HN what she wants so that makes for not an easy relationship
shall we say between them sometimes I’ve sat there and I feel like I’m the person
in between trying to keep the peace on both sides because I can see or I can
understand that HN’s not acting in a way that ZD’s interpreting or that ZD’s acting
in a way that HN is misinterpreting I feel like I am the one in between that
understands where they’re both coming from and tries to hold the relationship
together and improve it because it is a very special thing that ZD wants to learn
the harp and HN wants to teach her they’re both positive it’s just trying to make
sure that it works

Student: So ZD’s understanding of what her teacher says so you’ve mentioned
that she can misunderstand?

AD: yes

Student: so tell me what her understanding is like or what her misunderstanding
is like?

AD: ok its probably easier to start with the misunderstanding first because that’s
the more obvious the misunderstanding can come when ZD’s practised really
hard one week and wants to show HN what she can do and she plays it and part
way through HN might stop her and say can you play that a little bit louder or a
bit and immediately ZD sees that as HN’s being disapproving or HN’s not being
polite because she’s not waiting til the end of the song or the music before she
stops her so actually ZD interprets that as interrupting which is not a very polite
thing to do *laughs* and I have to say that’s what teachers do they will stop you
and it is frustrating because if you think you’re on a bit of a role and you’re
playing your absolute best and you think that they’re not listening and they’re
stopping you and telling you to replay that phrase in a different way it can be very
frustrating and ZD has in the past and if HN asks for something a little bit that
stretches ZD ‘cause HN you know that’s part of her job is to stretch ZD then if ZD
feels that she’s been stretched a little bit too much she can be quite sharp

Student: right can we just go back to you said that ZD thinks that HN isn’t
listening why do you think that why do you think that ZD has interpreted it in that
way?

Student: sorry is there any when you see that do you would you interpret that the
same way?

AD: I think when I see that that I interpret it as HN wanting to get the best out of
the sound in order to get the best out of ZD but I understand that ZD feels that
she hasn’t been listened to so it might be better say for HN to let ZD play it
through and for her just to say something very positive and then to go back to I’d
like to come back to a couple of few phrases now but even if she did that I think
73. ZD would still think oh here we go the criticism she takes it as criticism when
74. actually I’ve had to explain to ZD that’s HN’s job is to say let’s go back to this
75. phrase or that phrase it’s just a different style of teaching to some of her other
76. teachers

77. Student: OK so this sort of links in regarding ZD doing what her teacher says or
78. asks what is that like?

79. AD: ZD can try to do that and like I say she tries to please her teachers but if she
80. feels frustrated that she will she’s not really pleasing her teacher or doing what’s
81. she’s been asked to do she will she can get very frustrated and that comes out in
82. being stroppy being cheeky just letting her mouth go you know saying things that
83. are difficult to hear would be difficult for HN to hear and not want to respond to
84. you know to have to stay calm and she can sometimes cry she can go rigid with
85. her legs and her hands can go very rigid and tense she’ll try to hold her breath to
86. stop herself crying yeah that’s what she can be like

87. Student: so this again is linked in ZD’s behaviour at harp ensemble is like what?

88. AD: well that is more complex because there are other children involved there so
89. she’s having to listen to what’s going on with the other conversations and try and
90. keep up with what’s happening the dynamics between the whole group and
91. sometimes HN will say oh can you play that little bit louder or can you play that a
92. quieter or something and ZD won’t know whether that’s her or whether that’s
93. some other member of the group and you know we try to sort of say if you can
94. say ZD then ZD will know that is ZD that you’re talking to but that’s been a bit
95. difficult because HN doesn’t always remember you don’t always with things like
96. that and you know ZD doesn’t know whether it’s her or somebody else you know
97. being told well you’re not playing that bit right or you’ve not got the timing right or
98. whatever and ZD will take that as personal criticism and it’s not even anything to
99. do with her and she might even cry and sometimes that upsets the other children
100. because they don’t want to see ZD crying and they don’t understand why she’s
101. crying now the longer that they’ve been with her the more they’re understanding
102. her and the more she’s understanding the dynamics of the group and the easier
103. it is for them to work together but it’s still not easy

104. Student: so ZD’s relationships with the other children at harp ensemble what
105. are they like?

106. AD: she has a very friendly relationship with all the girls because the parents
107. are around quite a bit at harp ensemble up until very recently its maybe only
108. been going for half an hour here or an hour there and some of the parents have
109. to travel quite a bit to the harp ensemble we’re very lucky we don’t have to but
110. most of the other parents do have to travel quite a bit so they tend to stay they
might stay outside in the car and read a book or they might sit and listen to the
practise recently we’ve taken to dropping the kids off because they’re that bit
older and HN said she could cope with that now we can drop them off and we
maybe just go and get a coffee somewhere and come back later but that has
been growing and so as that’s been happening and the parents are ever so
positive and really lovely with ZD it means the children are learning to be
positive with her as well and the parents will say the children seem if the
children seem to run off without her one of the parents will say ‘scuse me
there’s ZD here come back you know come back you know there’ll actually
make a point of saying include ZD which is lovely I don’t have to say it they say
it and the children are learning to and so ZD is enjoying some of that it’s a safe
place if you like to experiment with friendships but because these little groups
you know we don’t have a sustained level of time you know with these
friendships they might only get ten minutes to have a little break between songs
they might go and have a drink together or they you know might go and get a
bit of fresh air outside or something like that so it tends not to be for a great long
length of time and the girls are gradually becoming less scared of ZD’s
blindness and talking to her and engaging her in conversation

Student: and when you say scared what sort of scared is that like?

AD: scared like I don’t know what to do and say here oh my gosh that person
can’t see what do I say now what do I do now I don’t understand how she is
behaving you know if ZD was crying about something like I say you know she
thinks HN’s given her into trouble when HN hasn’t sometimes ZD will say I want
to play the one HN’s got one big harp you know *gestures hand up high* pedal
harp and all the rest of them are small lever harps I want play the pedal harp
and the girls maybe just indulge her oh well yes she can play the pedal harp
because she’s poor ZD the blind girl you can play the pedal harp but HN wont
indulge her so sometimes she gets a bit fed up with that so it’s It’s my turn to
play on the pedal you know and she can get quite competitive and want to be
the best at playing something and it comes from not being feeling very secure in
the group doesn’t it partly she’s got a competitive spirit but also by not feeling
terribly secure

Student: and by secure that’s like what?

AD: I think just not even within in the group but in herself just this feeling of
being at ease

Student: OK are there differences between ZD and the other children at harp
ensemble?
148. AD: in some ways yes and some ways no all the children talk and laugh and
149. sort of participate in the conversations and ZD does too ZD might need more
150. time to listen to what's going on before she participates but she'll still say she'll
151. joke with them she'll talk with them but in other ways obviously she's more
152. dependent on them than they are on her for moving around if they have to go
153. and get a drink finding the drink she has to be taken to and told what the drinks
154. are and which one would she like and then given the drink and then she'll try
155. and find a place to put it whether that's a bottle of something so the empty
156. bottle goes in the bin so find the bin or else to find a sink to put the empty cup in
157. or something so she needs help and of course ZD is quite independent or like's
158. to be independent and so doesn't want that help so she's got this thing where
159. she in order to be part of the group she has to accept that help but at the same
160. time everything inside her rails against being that dependent on the girls no
161. matter how friendly and caring they are there are one or two that are very caring
162. of her and one or two that are slightly *gestures backing away putting hands up*
163. you know shy of her

164. Student: ZD’s enjoyment of harp ensemble what's that like?

165. AD: I think that she likes harp ensemble it gives her a sense of being part of a
166. group it gives her meaning to be part of that group and to have those
167. relationships she’s quite extrovert quite a party animal and so she does enjoy
168. and very often going and performing harp and being clapped at and being
169. treated like you’re very special and they are you know a very special little group
170. its very nice and ZD likes that
Appendix M

Pre-Social Story Interview: HN

1. Student: OK HN “laughs” harp ensemble what is that?

2. HN: it’s a group made up of the best elements from my students the most committed students and the most technically advanced for their age students we meet weekly fortnightly whenever we can get everyone together with the aim of competing in national and international competitions

3. Student: OK and you have ZD in your class your relationship with ZD what’s that like?

4. HN: ooh that’s a difficult question I always think I have had a very good relationship with ZD I’ve known her for about four years now I think so is there anything else you need to know?

5. Student: OK what kind of relationship is it?

6. HN: I think it’s a very positive relationship it can be challenging I think often ZD feels that she’s a cut above “laughs” and so you really do have to be on the ball all the time

7. Student: OK

8. HN: I think we have a good relationship and I think she does very well in harp ensemble

9. Student: if we can go back to challenging what sort of challenging is challenging?

10. HN: say you’re giving instructions etc. and you want x, y and z out of the people in the room you can sometimes get back chat from ZD

11. Student: OK

12. HN: and a lot of huffing and puffing

13. Student: right

14. HN: which can sometimes be quite challenging generally I just let it go rather than rising to the occasion

15. Student: right OK and ZD’s if we talk about her understanding her understanding of what you say what’s that like?

16. HN: it’s normally very good

17. Student: OK
30. HN: it would normally be very, very good I try to make sure that I’m not saying
31. anything that I don’t mean so so I try not say something in a way sort of
32. sarcastically or whatever whatever I always say exactly what I mean so that its
33. clear in black and white what I want to have done

34. Student: OK

35. HN: rather than sort of making a joke of it or whatever yeah just straight down the
36. line

37. Student: so when you say normally have there been times when you’ve thought
38. she might have misunderstood you?

39. HN: no but I think she can get I don’t think it’s that she’s misunderstanding what
40. I’m saying I think she can get worked up about things and she can take positive
41. direction the wrong way so she could take me saying could you close your hands
42. in close into the palm of your hand to make a better sound as your sound’s
43. rubbish

44. Student: right OK

45. HN: close into the palm of your hands because your sound is rubbish

46. Student: yeah OK so that kind of leads me to regarding ZD doing what you say
47. or ask what is that like?

48. HN: mostly she will do what you say or what you ask but she can do it with a bit
49. of *huffs*

50. Student: yeah

51. HN: which possibly isn’t the most positive thing in a group situation

52. Student: so her behaviour at harp ensemble what’s that like?

53. HN: as a general rule she’s fine but she can display possibly attention seeking
54. behaviour possibly maybe it’s not that at all but she can possibly do a lot of
55. huffing and puffing and if I’ll correct everybody but if I correct ZD she can get a
56. bit cross with me

57. Student: OK so attention seeking behaviour is that the huffing and puffing?

58. HN: yep, the huffing and puffing *makes huffing and puffing sounds*

59. Student: is there anything else?

60. HN: it’s always me
61. Student: right is that something she says?
62. HN: yes, you’re always correcting me
63. Student: right
64. HN: even though I’m correcting nearly everybody nearly all of the time *laughs*
65. Student: the relationships with the other children at harp ensemble what are they like?
66. HN: I think she’s got good relationships with everybody they all seem to get on very well
67. Student: right
68. HN: I think children with children especially bright children I think they communicate possibly better than children to adults
69. Student: right so if I can just go back to bright children so are the children
70. HN: the children in the harp ensemble are particularly bright
71. Student: OK
72. HN: and they are from a particular background we don’t have anybody that’s disadvantaged and we don’t have anybody from difficult backgrounds everybody is very middle England very bright would be the top end of the class yeah would be the higher achievers so mentally they’re all switched on I think I think that enables them to communicate better
73. Student: Right are there any differences between ZD and the other children at harp ensemble?
74. HN: ZD is more able
75. Student: OK so what are the differences?
76. HN: musically ZD is far more advanced than the others and she is more able and I think ZD possibly finds it difficult to be tolerant of those less able and having to keep going back over things and back over things frustrates her I think
77. Student: OK if we can just go back to if she’s intolerant what’s that like?
78. HN: it’s the huffing and puffing again back to the huffing and puffing and slightly sort of teenager behaviour
79. Student: OK
91. HN: but I think its possibly that she it could be down to the fact that she can’t see
92. what’s going on in the room so she can’t see why I keep having to go back and
93. because she is more musically perceptive than everybody else in the room she
94. can’t see why everybody else keeps making the same mistakes

95. Student: OK right and finally her enjoyment of harp ensemble what do you think
96. that’s like?

97. HN: I think she really enjoys it I think she gets a lot out of it and all the activities
98. we do she throws herself into fully so I think she gets an awful lot out of it I think
99. it’s probably of quite an important part I think it would having the harp ensemble
100. makes a big difference to just having lessons and doing her exams I think it
101. gives her much wider scope and more access to things yeah so

102. Student: great well thank you very much

103. HN: you’re very welcome
Appendix N

Social Story for Harp Ensemble

Written by AD and ZD (Original format Braille)

“When I arrive at harp ensemble I meet the other girls and their parents. Everybody looks at one another. The importance of looking at one another is to greet each other. When people look at each other at the beginning of harp ensemble they smile to show that they are happy to see one another.

I say a general ‘hi’ and wait for people to reply. Then I know who’s in the room. People smile at me when they say ‘hi’ to me because they are pleased to see me. HN asks us to come into the music room. The girls talk to each other they know who they are talking to because they are looking at the person that they are speaking to and standing near or next to them. If I am far away from people talking and they are not talking loudly I should assume they are not talking to me. This is not because they don’t like me it is because they are not near me and they are not looking at me and they are not expecting me to join in with their conversation.

Remember my hearing is much better than most people’s. People don’t expect me to be able to hear them when they are far away from me. If I want to join in the conversation then I should go up to them and say something like ‘what are you talking about?’ then they know that I want to be part of their conversation.

In the music room whilst we are getting ready the girls look at their music and tune their harps. I tune my harp. When the rehearsal starts H conducts by counting the beat. She also looks around the room at every harpist to make sure they are playing the right notes, right volume and right tempo etc.

While she conducts she is smiling which shows the harpists that she is enjoying their playing. H stops everyone by saying that something is wrong. She uses people’s names to let them know that they need to change the way they are playing. If I don’t hear my name I should assume H is not talking to me, therefore I don’t need to feel upset. If H says something to me and her voice is loud she is being loud because there are lots of people in the room, not because she is angry.

Sometimes I will need to say something or ask a question. If I do this if the other people are speaking I may not be heard and they may not hear me and not answer my question. Then I feel like I am being ignored. Instead I wait until there is a gap of silence in the conversation and ask question in a clear voice. The girls will then look at me and realise I am talking and answer my question.

When people are talking in a group, people talk in turns. People know when it’s their turn because they look at each other. I know when it’s my turn to speak because I
wait for a gap of silence. H sometimes asks the group a question. I am great at putting my hand up which the other children do as well. If H says my name she wants me to answer the question. If I need H’s attention I can get it by putting my hand in the air even when other people are talking. I just need to wait until H says my name and then I can say what I need to. If I want to talk to someone I should say their name so they know I want to talk to them. If someone wants to talk to me they will say my name and start a conversation.

I need to be aware of my face shapes. People can see expressions I make and I know how much they expressions mean to sighted people.

I am doing well at harp ensemble and H thinks I am very musically talented. I am an important part of the group and other girls learn a lot from me.”
### Appendix O

**Table ii: Post Social Story Data**

ER = Expected Response  
DR = Different Response

<table>
<thead>
<tr>
<th>Theme</th>
<th>Expected Responses</th>
<th>Actual Response ZD</th>
<th>ER</th>
<th>DR</th>
<th>Actual Response AD</th>
<th>ER</th>
<th>DR</th>
<th>Actual Response HN</th>
<th>ER</th>
<th>DR</th>
<th>Actual Response</th>
<th>ER</th>
<th>DR</th>
</tr>
</thead>
</table>
| a. Perception of Social Story experience | No baseline therefore no expected response | ‘Kind of distressing – showed me where I was going wrong’  
‘Quite a few things highlighted’  
‘Showed me where to go on’  
ZD particularly noted piece of information she learned about not joining in conversations happening far away from her, even though she could hear the conversation | | | ‘Interesting to see ZD’s responses…lot’s of things we take for granted’  
e.g. ZD not previously aware that people smiled at her and liked her  
or ZD not aware HN smiled when conducting ensemble  
ZD upset by experience, made her sad that she was different  
ZD since regulating social self in other settings – AD sees this as a positive thing | | | (not asked question) | | | |

1. Perceptions of harp ensemble | ZD: More positive perception due to increased understanding of environment  
AD& HN: similar perceptions as before | ‘It’s been getting better’  
‘Less alienating’  
ZD was pleased that another girl has asked specifically to talk to her | ✓ | | A group of five girls including ZD  
Social story helping ZD think about how she responds in harp ensemble | ✓ | | | ✓ | Two groups, junior and adult, get together to prepare for concerts, competitions and socialise | ✓ |
### 2. ZD’s relationship with HN

| ZD & AD: | ZD more chatty with HN ‘making more of initial interaction [with HN]’ ‘ZD experimenting with new information and how to progress this relationship with her teacher’ |
| ZD & AD: More positive now that ZD understands that HN does not want to criticise her |
| HN: aware of a positive change in their relationship |
| ‘She’s tedious…but nice’ [HN] changes her mind a lot but its normally for the better because the ensemble sounds good’ |

**✓** Very positive relationship

### 3. ZD’s understanding of HN’s communication

| ZD & AD: ZD aware of visual communication between HN and group therefore ZD less frustrated and no longer misinterpreting HN |
| HN: aware of a positive change in ZD’s understanding |
| ZD following instructions and understanding that they are not criticisms but will help ZD |

**✓** ZD following instructions and understanding that they are not criticisms but will help ZD

| HN now addressing ZD by name therefore ZD able to understand when HN is speaking to her, or other children |
| ZD trying to follow directions and do what her teacher says |

**✓** HN now addressing ZD by name therefore ZD able to understand when HN is speaking to her, or other children

| ZD’s learning not to take HN making group repeat sections of music as personal criticism |
| ZD ‘pretty much’ does what HN asks, if not she does if HN insists |

### 4. ZD’s relationships with other children in harp ensemble

| AD & ZD: ZD more confident in making relationships with other children ZD happier as a result of making friends |
| ‘It’s getting easier some of the girls are really nice’ ‘They’re actually trying now they’ve actually got to know me’ |

**✓** ZD asked to socialise with other member of the group outside of harp ensemble, ZD excited about this

| ZD being included with the other girls, involved in conversations and activities separate from the parents |

**✓** ZD being included with the other girls, involved in conversations and activities separate from the parents

**✓** Very positive environment ZD gets on very well with all the girls, particularly BC who she has started seeing socially out of harp ensemble

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P07227341  SALT 3201  ‘Augmenting the awareness of social communication in a congenitally blind child: A case study’
HN: aware of a positive changes in ZD’s relationships with other children

‘Girls are getting friendlier’
‘ZD’s more positive about being friendly with them’
ZD now understands that the other girls are friendly with her,
ZD now understands she has friendships at harp ensemble

5. Perceived differences between ZD and other group members

HN & AD: Less differences perceived in ZD from other children

(not asked question)

‘Still a long way to go...but interesting [to see the changes] since the social story’
ZD monitoring and questioning social communication in other contexts: AD interprets this positively

More musically able than most of the group, on par with one other girl

6. ZD’s understanding of environment at harp ensemble

ZD: Increased understanding of what is taking place in harp ensemble

ZD understands how important sight is in communication
Understanding still sometimes unclear but can understand when people are unhappy
‘Normally good [understanding]’

(not asked question)

(not asked question)

7. ZD’s behaviour at harp ensemble

HN, ZD & AD: Less challenging behaviour:
reduced ‘crying’, ‘being cheeky’ and other frustration related behaviour

‘I try to get on with things the best I can’
ZD happily describes a time when she might be persuaded to be naughty with the other children playing whisper games.

Positive behaviour, no information received from HN which suggests anything contrary to that

‘Very good...can’t fault her’
‘Now she accepts the situation’
| 8. ZD’s overall enjoyment of harp ensemble | ZD: Increased enjoyment at participating in group and understanding all aspects of communication taking place. AD & HN: aware that ZD’s enjoyment of harp ensemble has increased. | ‘It’s been really enjoyable over the past week or two’ ‘I’ve been more invited into stuff’ ‘I’ve been sort of respected for what I’m worth in harp ensemble’ | ✓ ZD enjoying group and friendships | ✓ ‘I think she enjoys it’ HN perceives that ZD may sometimes find harp ensemble boring and frustrating because she is more able than the other children. |
Appendix P

Post-Social Story Interview: ZD

1. Student: ready OK ZD I’m gonna ask you the same questions as I asked you last
2. time with one different question which we’ll begin with so that is making the social
3. story what was that like?
4. ZD: it was kind of distressing because it showed me where I was going wrong in
5. life but and there were quite a few things that were highlighted but it showed me
6. where to go from here kind of so yeah
7. Student: OK what was that like?
8. ZD: because it was like all about not talking to someone if there about the room’s
9. length away which I had an awful habit of doing so you know not being a bit of a
10. big ears it showed me or and just to talk plainly with people if you know what I
11. mean like nothing you know nothing sort of nothing sort of distant if you know
12. what I mean
13. Student: distant like what?
14. ZD: just like waffling on
15. Student: OK and your teacher HN oh sorry i’ve missed a question out harp
16. ensemble so harp ensemble what is that like?
17. ZD: harp ensemble well it’s been getting better it’s a bit less alienating yeah so
18. yeah I mean there was a concert on Saturday the practise was really good but
19. yeah it was tedious but good just like HN *laughs*
20. Student: so alienating what kind of alienating was that like?
21. ZD: cos everyone seemed be thinking I was a monster and not really talking to
22. me as they did with each other
23. Student: OK and is it like that now?
24. ZD: not quite its sometimes a little bit like that but it isn’t much like because at
25. least you know they’re talking to me personally because there was this girl there
26. was this girl called B in the concert whose in our ensemble and she asked 27.
27. especially to talk to me and we were in a church and the sort of rooms were open
28. we went into the vestry and had a long chat
29. Student: oh that’s great and what about your teacher HN what is she like?
30. ZD: she's like I said she's tedious but you know nice she she likes to change her mind a lot but it's all it's normally for the better because the ensemble sounds good

33. Student: OK

34. ZD: yeah

35. Student: Ok and that's nice and what's that like what kind of nice is that?

36. ZD: tuneful rather than

37. Student: sorry I was thinking about your teacher HN when you said she was nice

[overlap]

38. ZD: oh sorry

39. Student: nice like what?

40. ZD: she's sort of gets into things a lot but yeah

41. Student: and what kind of gets into things is that like?

42. ZD: well she gets into all these different competitions in Wales like eisteddfods stuff

44. Student: OK and your understanding of what HN says what's that like?

45. ZD: it's kind of sometimes it's a little bit you know sometimes she says things like come on stay in time I'm like OK so I try to you know listen to someone else more than myself like HN says and it normally improves because normally it's for the better that she's talking about that with us

49. Student: us or you?

50. ZD: well any of us really that's just an example

51. Student: making friends at harp ensemble what is that like?

52. ZD: it's getting easier really all of them are really nice girls and yeah

53. Student: easier like what?

54. ZD: well at first everyone kind of tried to avoid me but now they're actually trying now they've actually got to know me a bit better and it's you know getting easier to make friends

57. Student: OK easier to make friends ok so what kind of easier is that like?
58. ZD: easier well I told you didn’t I so
59. Student: OK your understanding of everything that happens around you at harp ensemble what’s that like?
60. ZD: well after the social story I’ve realised how important sight is to people who have it have it available if you know what I mean
61. Student: yeah so what’s your understanding like?

*background noise*

62. ZD: sometimes wait a minute I just got distracted
63. Student: that’s ok
[overlap]
64. ZD: anyway
65. Student: do you want me to say the question again?
66. ZD: yeah
67. Student: your understanding of everything that happens around you at harp ensemble what’s that like?
68. ZD: well it’s like sometimes it’s a little bit unclear what people are doing cos sometimes it sounds like someone’s eating when they’re not
69. Student: let’s think about the last two weeks of harp ensemble what was your understanding of everything that happens around you at harp ensemble what’s been like?
70. ZD: well sometimes it’s actually good understanding and sometimes it’s a little bit negative it’s normally good yeah

71. Student: and your behaviour at harp ensemble what’s that like?
72. ZD: thing is I just try to get on with things as much as I can but sometimes I get easily distracted see if L see if we’re in the middle of a concert yeah if L says don’t put your harp up pass it on i’d probably pass it on to H *laughs* probably because someone passed it on to L but oh well yeah

73. Student: and your behaviour at harp ensemble what’s that like?
74. ZD: thing is I just try to get on with things as much as I can but sometimes I get easily distracted see if L see if we’re in the middle of a concert yeah if L says don’t put your harp up pass it on i’d probably pass it on to H *laughs* probably because someone passed it on to L but oh well yeah
87. Student: and your enjoyment of harp ensemble what is that like?

88. ZD: yeah it’s really it’s been really enjoyable over the past week or two

89. Student: what sort of enjoyable is that?

90. ZD: well pass well if you know what I mean because it’s kind of hard to explain

91. but I’ll do my best

92. Student: OK thank you

93. ZD: what I’m gonna say is that let’s see how do I explain this *laughs* so people

94. have been you know I’ve been like you know I’ve been more invited into stuff

95. rather than being alienated and just doing that stuff that and just doing the stuff

96. that the ensemble are doing and no further cos I was in a trio and a duet and

97. then performance of oh come all ye faithful in the Christmas concert *whispers*

98. is that OK

99. Student: yeah that’s great is there anything else that you want to tell me about

100. your enjoyment at harp ensemble?

101. ZD: sort of yeah it’s sort of tagging on to that the thing is I’ve been sort of

102. respected for what I’m worth in the harp ensemble

103. Student: good

104. ZD: because I thought I’d be snowed in yesterday but I wasn’t which was for the

105. better so you know

106. Student: good stuff shall we finish there

107. ZD: yeah

108. Student: OK thank you very much ZD
Appendix Q

Post-Social Story Interview: AD

1. Student: right I’m going to ask you the same questions as I asked you last time
2. with the addition of one question which is making the social story what was that like?
3. AD: when we talked through what was happening  (ZD enters room)
4. Student: hello ZD we’re just having an interview
5. ZD: oh sorry (ZD leaves room)
6. AD: I didn’t know whether you wanted to start again
7. Student: oh no that’s alright
8. AD: yeah when we talked through what happened through the whole session and
9. ZD helped me to braille it it was quite interesting to see her responses to things
10. and to realise that there were a lot of things that perhaps we take for granted that
11. she would understand that she didn’t understand I mean I think the thing that
12. really struck me was when we talked about her going into the room and saying
13. hello to everybody and how people smile at her when they see her and of course
14. she didn’t know that and how that was very profound really because you take a
15. lot of confidence if you like from how people react to you nonverbally if they smile
16. at you smiling is such an important part of our language and she doesn’t have it
17. and she hadn’t realised that people smiled at her and she hadn’t realised that
18. people liked her and I think that there were times when we explained that ZD that
19. HN for instance was smiling at her or smiling when she was saying something
20. when she was telling her what to do and ZD hadn’t realised that either so I think
21. that she put perhaps a more negative spin on that piece of social interaction I
22. mean she wasn’t upset by it she hadn’t come out upset she just possibly hadn’t
23. been as affirmed in herself as I thought she might have been
24. Student: right and is there anything else about making the social story?
25. AD: it did upset her to talk through things in quite a lot of detail
26. Student: what kind of upset was that like?
27. AD: well she might have felt a bit defensive I suppose when we were talking
28. through what peoples’ reaction might be to for instance just something like
29. because her hearing is so good how she copes with being able to hear things
30. that like conversations that other children aren’t aware she’s listening to and
31. when she can join in a conversation when she must just keep it to herself and
32. when she can join in a conversation when she must just keep it to herself and

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33. again we take our cues from our social interaction if someone’s speaking very
34. confidentially to someone else we don’t tend to walk in and I mean some people
35. do but most of us wouldn’t tend to walk in and sit down and you know try and join
36. that conversation so you know I tried to describe to her what was happening
37. when two of the children were trying to speak more confidentially at a distance
38. ZD hadn’t really clicked about that I think she got upset I think it made her sad to
39. think that she was perhaps not able to read the signs and not able to socialise as
40. easily as the others were finding it I think she knew it in her head when we
41. started kind of flesh out what that looked like in practise it did make her sad

42. Student: ok so these are the questions you’ve heard before harp ensemble what
43. is that like?

44. AD: I can’t even remember what I said the last time about ZD’s experience of
45. harp ensemble it’s when ZD goes and practised with other children four other
46. young girls she’s one of the eldest amongst the five of them and she does enjoy
47. making music with the others and she I think she is enjoying getting to know the
48. others and I think the social story is helping her in terms of beginning to ask
49. about the social situations and think and think about how she responds

50. Student: and ZD’s relationship with her teacher what’s that like?

51. AD: do you mean after we did the social story?

52. Student: yeah

53. AD: right well she said that she had a very good lesson when she had a lesson
54. with her teacher

55. Student: what about in harp ensemble?

56. AD: in harp ensemble I think that she generally seemed to be happy with what
57. happened at the second you know the harp ensemble afterwards she went in I
58. remember her going in and chatting more to her teacher and making more of that
59. sort of initial interaction and the lesson as well because she had an interim
60. lesson with her teacher before she had the harp ensemble and she was chatting
61. so much with her that I thought that they’re not gonna have enough time to do
62. the lesson you know but that was probably quite a necessary thing because
63. again she again was just experimenting with new information and how to
64. progress this relationship with her teacher

65. Student: and her understanding ZD’s understanding of what her teacher says
66. what is that like?

67. AD: well I think that her teacher noticed her teacher has spoken to her ZD and
68. addressed ZD more and so ZD’s sort of known what’s going on when she was
69. when it was her that her teacher was talking about and when it wasn’t her
70. because sometimes that’s confusing and she hasn’t in the past known you know
71. if a direction for instance was meant for her or for somebody else and I think that
72. her teacher has perhaps is you know more conscious of saying it now more
73. consciously making an effort to say it and ZD is responding to that
74. Student: good OK and regarding ZD doing what her teacher asks or says what is
75. that like?
76. AD: well I think that she’s that she is trying to do what you know she’s trying to
77. she’s been asked to arrange a harp solo that’s now turned into a duet that’s fine
78. and she did the arrangement and she practised it and I didn’t have to say are you
79. going to practise you know she went off and did that herself because she wants
80. for her part she wants to take responsibility for her part in the ensemble so I think
81. yeah I have seen a change there with that I haven’t ever had to say to her have
82. you practised because you have this concert coming up or something like that
83. Student: great and ZD’s behaviour at harp ensemble what’s that like?
84. AD: I think in general the girl’s seem to be getting friendlier all of them seem to
85. be getting friendlier with each other the more that they do together the more
86. concerts and everything that they do and so ZD’s more positive about being
87. friendly with them and I think she understands that they are being friendly with
88. her I think she actually thinks now that she has friendships there
89. Student: right so her behaviour what’s that like?
90. AD: behaviour I think she’s quite positive I haven’t heard anything to the
91. detriment I haven’t had a conversation with HN actually about how HN finds her
92. behaviour but ZD seems more positive
93. Student: sorry to interrupt you there but we’re getting onto her relationships with
94. other children so the her relationships ZD’s relationships with other children at
95. harp ensemble you’ve sort of talked a bit about that what are they like?
96. AD: well one of them has asked to meet up with her socially outside of harp
97. ensemble and we’re going to do that today actually later so she’s excited about
98. that and last night they had a concert and she went off with the other children it
99. was really nice she just went off with them and she was there sitting with four
100. other children in another room sitting there chatting and I was chatting with the
101. other parents and you know I didn’t have to worry about her and I didn’t wasn’t
102. thinking should she be sitting with me or whatever and there have been times
103. when she would have been left to sit with me so I think because perhaps she’s
104. feeling a bit more positive the girls are also responding to that and saying I’ll
105. take you one of them said lets go next door and took her next door and the four
of them sat last night after the concert in a little kind of ante room because they
didn’t want to sit with the oldies and they had a drink and something to eat after
the concert in another area and she had been included in that and she went off
did that and that was really nice

Student: are there differences between ZD and the other children at harp
ensemble?

AD: yes I mean I still think that she’s got a long way to go but I think it’s been
interesting watching what’s happened since the social story because she was in
another social context a different social context altogether with another person
that’s she’s known child same age which she’s known for quite a long time and
this week we met up with them quite by accident really and ZD was playing with
this child and she was talking with her and whatever and afterwards she said to
me how did I do socially was there anything that I need to think about and
that I think that was a direct result of having the experience of thinking about
what happens with the children and young people in the harp ensemble you
know she’s now thinking about what other friendships as well so she’s taking
what she’s learning in the harp ensemble and beginning to apply it to other
relationships so that’s very positive for her to ask me you know because
normally she would be quite defensive you know I don’t need to know anything
or I don’t care that sort of thing but saying what can I learn from that is there
anything I need to be learning socially is a huge step forward really

Student: so finally ZD’s enjoyment of harp ensemble what’s that like?

AD: oh I think she is enjoying very much I watched her last night just taking part
with them in the concert and then afterwards going off and being part of the little
group of girls you know sitting chatting with them and whatever and I think she
gets a lot out of that friendship you know or set of friendships and they are all
very nice little girls you know together it’s a lovely little group so yeah *smiles*

Student: good

AD: it’s been a good thing and I’m beginning to think myself that I need to this in
other contexts as well that might be really helpful to her but I’m tending to think
that we’d have to do it slowly and gradually rather than jump from one thing to
another because I don’t want for her to start to feel too anxious about it

Student: great good stuff well thank you very much

AD: thank you very much

Student: we’ll leave it there
Post-Social Story Interview: HN

1. Student: there we go good shot of the cat

2. HN: the cat wants to be in it too

3. Student: OK so thank you again *laughs* I'm gonna ask you the same questions as last time so we'll start with harp ensemble what is that?

4. HN: It's a group well there's two groups junior and adult we get together try to get together every week to meet to prepare for competitions put on concerts and socialise

5. Student: OK and your relationship with ZD what is that like?

6. HN: I think it's very positive on both sides actually I think I think she enjoys everything we do sometimes it can be challenging but you just have to be firm and slightly insistent and don't be put off by her

7. Student: OK

8. HN: don't take any of the attitude if she gives you any

9. Student: if we can think about the last two weeks since so she's had the social story what has that been like?

10. HN: think oh well we haven't had ensemble since then I don't think have we

11. Student: oh sorry OK it'll be the last two ensembles so she actually had it four weeks ago

12. HN: yep and we've had the concert yeah she was very positive through the concert we only had a little bit of huffing and puffing but that's because we were working under extreme pressure because a lot of the adults hadn't unable to come so the juniors had to put on a whole concert where until four o'clock that afternoon they were only playing three pieces so but she performed very very well and she worked well with B when they did their duet and with H

13. Student: great OK ZD's understanding of what you say what's that like?

14. HN: I think sometimes she gets irritated because we have to go back over and over things but I think she's learning more now that it's not a personal criticism of herself but it's to improve the group situation and to make the overall group better the difficulty for ZD is like I've said before she is more able than the majority the majority of the others in the group *laughs* which can make it challenging and possibly a little bit boring
32. Student: regarding ZD doing what you say or ask what’s that like?
33. HN: she pretty much does it pretty much
34. Student: *laughs* I feel like I’m repeating myself
35. HN: yeah pretty much does it if she doesn’t you just have to insist *laughs*
36. Student: ZD’s behaviour at harp ensemble what’s that like?
37. HN: very good you know you can’t fault her really we’ve got much less of attitude
38. now which I think’s a positive thing
39. Student: and so just to clarify the attitude what’s that like?
40. HN: before it was very much huffing and puffing and a bit teenagery but now it’s
41. more just accepting of the situation you know that we are going to be going over
42. things more than once
43. Student: OK great what about ZD’s relationships with the other children
44. HN:I think she gets on with them very well they all get on with each other very
45. well it’s a very positive environment I think she’s particularly really bonded with
46. BC and I think they’ve been swimming and playing at each other’s houses and all
47. that kind of thing so I think that’s probably a positive thing for both of them
48. Student: yeah brilliant are there any differences between ZD and the other
49. children at harp ensemble?
50. HN: she’s possibly more able than all of them about apart from BC who she’s
51. more on a level with
52. Student: and what about ZD’s enjoyment of harp ensemble what’s that like?
53. HN: I think she enjoys it I think she enjoys it even though sometimes she
54. probably think it’s a bit *huffs* just because she’s a little bit in front of everybody
55. else and then you need a leader and you need people who are able to carry the
56. ones who are less able so
57. Student: great well that’s everything zoomed through those questions
58. HN: oh fantastic excellent
59. Student: so yeah thank you very much
60. HN: brilliant great stuff you’re very welcome
61. Student: I’ll just move the cat
Appendix S

Record of Personal Communication with Ian Bell

The researcher would like to thank Ian Bell, Lead Speech and Language Therapist at RNIB’s Rushton School, for his support and input into this research project.

Below is a record of personal communication between the researcher and Ian Bell:

20 September 2010: email
23 September 2010: phone call
23 September 2010: email
27 September 2010: email
09 January 2011: email
09 January 2011: email
13 January 2011: phone call

A copy of the emails has been handed in to De Montfort University separately to the project in order to maintain Ian’s right to confidentiality.