

# Eliciting the views of disabled young people on friendship and belonging: Authentic voices for action research engaging schools in change towards social inclusion.

Submitted by Claire Hoskin to the University of Exeter as a thesis for the degree of Doctor of Educational, Child and Community Psychology, May, 2010.

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## Overview of Thesis

This small-scale study is positioned within a social constructionist interpretive paradigm using a mixed methodology employing principles of adapted grounded theory, simple scale-based questionnaires and action research. Fourteen disabled young people from one specialist and three secondary mainstream settings were interviewed using semi-structured interviews to gain their views on friendship and belonging in schools. Three groups of parents, TAs, SENCos and allied education professionals engaged in action research to examine these views, their own views and values and those of young people in their families and schools in order to better understand the sensitivities and subtleties of successful social inclusion and to consider change to whole school practice.

The limitations that non-disabled adults unwittingly 'construct' that act as barriers to friendship and social inclusion were explicitly recognised in this interpretive research as a contribution to informing practice and theory in this domain (O'Hanlon, 2003; Higgins, MacArthur & Kelly, 2009).

Paper One focuses on the views of disabled young people and the meaning and importance they placed on friendship and social relationships in their lives. These views were elicited through initial focus groups and then individual semi-structured interviews. Interviews were digitally recorded

and analysed qualitatively using NVIVO and an adapted grounded theory methodology.

Paper Two describes using these views as stimulus for action research to bring about change towards improved social inclusion in a specialist and two mainstream settings situated in the Southwest of England. Groups of parents, senior management, SENCos, TAs and other education professionals met formally three times over a four month period. These groups examined vignettes selected from data from paper one, engaged in debate and discussions, interviewed disabled young people themselves, formulated key concept maps leading to revised theoretical frameworks, reflected and evaluated the process of the action research and considered practice change or further research.

In order to explore the understanding and meanings disabled young people accorded to friendship and a sense of belonging and the importance of this for their successful social inclusion my research addressed the following research questions.

1. What opportunities do physically disabled young people feel they have to make positive relationships with adults and peers in mainstream or specialist settings?
2. Why are friendship and a sense of belonging important for disabled young people?

3. How can we, as educational professionals, learn from the 'autobiographical voice' of these young people to improve their opportunities for friendship and belonging to enhance their experience of social inclusion?

## **Research design and methods**

For the first part of my research I used an adaptation of a constructionist grounded theory approach in line with the method described by Charmaz (2006, 2008). The distinctive properties of this method were that it involved me in data analysis while collecting qualitative data. This initial data analysis informed and focused further data collection. For the second part of my study I used an action research approach (O'Hanlon, 2003) and findings were further analysed using a thematic analysis (Braun & Clarke, 2006).

## **Brief summary of findings**

Findings included that young people in specialist and mainstream setting highly valued friendships but that sustaining friendships in the wider community was often problematic for those participants who attended schools outside their local community. This mainly affected the specialist setting students but was also recognised as an issue by some of the mainstream parents who lived outside the school catchment area.

Findings also revealed that young people gained their sense of belonging from the positive relationships they formed with TAs and teachers as well as friends. In order for friendship and positive social inclusion to develop, however, participants required schools to provide a supportive environment of accessible rooms, doors and lifts and adults who trusted them to have the competency and agency to manage their social times and spaces with choice and autonomy.

The issue of 'surplus visibility' was highlighted by Lara and Jackie who spoke of an experience of school where lack of choice concerning 'where' and with whom to spend break times limited their friendship opportunities and sense of well-being and inclusion. This was compounded by an expectation of compliance by adults and automatic assumption of their 'belonging' to a 'disabled' group despite differences of sex, gender or common interests. The participants valued genuine connection through humour, interests and social support and were active in their seeking of private time for talking with friends. Schools that provided a range of highly social or quieter more private locations for students were highly valued.

The second action research stage was a continued process of seeking to hear authentic voices, in depth discussion and reflection on what we were learning from young people combined with our own knowledge, values, and beliefs. This led to the development of conceptual models and

practical change intentions to promote social inclusion. Intentions to change included

- Developing alternative social rooms with minimal TA presence
- Including disabled young people in TA selection processes
- Involving parents in reviewing the school inclusion policy
- Establishing a regular parents' support group
- A commitment to keep listening to young people's voices and preferences on key matters rather than 'assuming that we already know!'
- Lengthening the lunch break in the specialist setting to ensure time for socialising and friendship building

These commitments to change demonstrated that schools were able to engage successfully in the action research process, valued parents' contributions further and were willing to change practice towards greater social inclusion of disabled young people and parents.

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## **Paper One**

**Eliciting the views of disabled young people on  
friendship and belonging.**

## **Abstract**

This small scale study is positioned within a social constructionist interpretive paradigm using a mixed methodology employing adapted principles of grounded theory and a simple scale-based questionnaire.

Fourteen disabled young people aged from thirteen to seventeen years old from one specialist and three secondary mainstream settings were interviewed using initial focus groups and then individual semi-structured interviews.

Findings were that young people valued friendships highly and gained their sense of belonging from the positive relationships they formed with TAs and friends. In order for friendship and positive social inclusion to develop, however, participants required schools to provide a supportive environment of accessible rooms, doors and lifts and adults who trusted them to have the competency and agency to manage their social times and spaces with choice and autonomy.

Young people managed their physical impairments including pain with skill and minimal anxiety but when a sense of being listened to, valued and belonging was not achieved it was physical and attitudinal barriers that were seen as the disabling factors within schools not the impairments themselves.

Overall, however, young disabled people in mainstream settings reported a varied and empowering community social life including dance, drama and wheelchair tennis and football. Although participants in the specialist setting reported having a strong sense of friendship and belonging in school five out of seven participants reported that they rarely saw friends out of school and this was described as occurring due to difficulties with transport and arrangements including that their friends' houses did not have wheelchair access.

The young people in mainstream settings were confident users of social networking, emailing and online Xbox communication. The participants interviewed from the specialist setting were less confident and tended not to use these mediums to communicate outside of school despite having sufficient IT skills to do so and expressing a desire to keep in touch with their friends. They reported being unsure if they had 'permission' to do this in contrast with mainstream pupils who managed their own social networking autonomously.

This research highlighted the need to actively listen to young people's views, preferences and expert knowledge on the matters that concern them. In order for successful social inclusion to occur disabled young people must have the choice, time and space to be with friends away from adult facilitators when they choose and to lose their 'surplus visibility' in

order to have normal teenage private time to build close friendships with a range of chosen peers. Whilst specialist setting pupils reported a sense of belonging and successful friendships within school this had not been their experience in the wider community. Ways of ensuring greater participation and belonging in the wider community for young physically disabled people would be a valuable area for further research and evidence-informed practice development.

# Introduction

## Context

The Salamanca Framework for Action (UNESCO, 1994) and the UN Convention on the Rights of the Child (UNICEF, 1989) have created an international culture for inclusion by arguing that all forms of segregation are 'ethically unacceptable' (O'Hanlon, 2003). Since the Warnock Report (DES, 1978) there has been a greater acceptance and recognition of diversity in mainstream settings. This has been supported by a raft of government publications including Excellence for All Children: Meeting Special Educational Needs (DfEE, 1997) which focused on meeting children's needs in their local schools. The Education Act (DES, 1981) and the Special Educational Needs and Disability Act (SENDA) (DfEE, 2001) also recognised and supported the possibility of meeting diverse needs in the local community rather than specialist or segregated schooling.

Whilst this legislation suggested an increasing government commitment to inclusion of disabled pupils in mainstream settings there remains an acknowledgment of the dilemma of schools' anxieties about league tables and results in the climate of a governmental 'raising standards' agenda. Thus some schools may be dissuaded from making the 'reasonable adjustment' required for pupils to experience full social inclusion (Kelly & Norwich, 2004; Thomas & Vaughan, 2004; Norwich, 2008). The literature

about inclusion ranged from the functionalist views expressed in government legislation to a more insightful exploration of the dilemmas of inclusion which acknowledged that inclusion is a politically, socially and morally complex issue (O'Hanlon, 2003, Oliver, 1996; Thomas and Vaughan, 2004; Topping & Maloney, 2005, Norwich, 2008).

As a Trainee Educational Psychologist (TEP) working for a psychology service in the Southwest of England I work in mainstream and specialist settings. I work collaboratively with children, young people, families, schools and other agencies in order to enhance emotional well being, overall development and achievement. In this role I am ideally positioned to listen to young people and families in order to secure more positive outcomes.

### **Rationale and broad aims**

This small-scale study, within an interpretive paradigm, is concerned with gaining young people's personal views of friendship and belonging in school. I have chosen to listen to young people whose thoughts and feelings have traditionally not been thoroughly researched and who may experience marginalisation in their schools and communities (Badham & Wade, 2005; Beresford, 1997; Clarke & Venables, 2004; Lewis & Lindsay, 2000; Morris, 1991). In specialist settings a disabled child may have a greater sense of belonging to a community and a peer group that has a

similar cultural set of norms and understandings. Is specialist provision, however, more likely to lead to lower expectations, and isolation? Do these young people experience an appropriate and specialised environment that is able to meet their complex needs or experience limited access to a diverse range of peers and adults?

## **Selected literature and theoretical aspects**

Whilst much psychological research focused on the views of teachers, professionals and parents the views of the child themselves was rarely thoroughly explored. Although Norwich and Kelly (2004) examined the views of children on inclusion, labelling and bullying a key word search using PsychInfo and EBSCO revealed a lack of further psychological research eliciting the voice of young people with additional needs especially in the area of friendship. Young people who have physical impairments, when coupled with speech difficulties as in cerebral palsy, may further find their views are not sought or represented accurately (Lewis & Lindsay, 2000; DCFS, 2009). There may be a fixation on their medical needs, especially a view of the child as 'tragic victim', medical model, rather than an understanding of the socially constructed nature of disability (Oliver, 1996; Thomas & Vaughan, 2004; Topping & Maloney, 2005). Robinson and Stalker (1998) confirmed this belief,



*“whilst there is a well established body of knowledge about the way parents experience life with a disabled child, children’s own accounts of their lives are largely missing, their voices have not been heard”*

Robinson and Stalker (1998, p.7)

So children’s voice, despite much legislation and positive rhetoric, may be in practice marginalised and the opportunities and support given to them in mainstream and specialist settings may not be what they would choose if they were actually asked (Asprey & Nash, 2005; Billington & Pomerantz, 2004; Rustemier, 2002).

### **Inclusion complexities**

Developing meaningful theory and practice in the domain of inclusion is complex. The issue of difference is central to any discussion on inclusion. Norwich (2008) contended there were three main dilemmas for inclusion

- The identification dilemma – whether to identify students as having SEN/disabilities or not?
- Curriculum dilemma – how much of a common curriculum is relevant to these students?
- Placement dilemma – can appropriate learning take place in mainstream schools or not?

For this study the identification dilemma was important as for most physically disabled young people their physical impairment is highly visible and, therefore, they have no choice in being identified as different from their peers. Therefore, the concept of 'surplus visibility' (Patai, 1992) was pertinent and may be experienced on a daily basis. The concept of 'surplus visibility' was illuminative in that Patai contended that when 'powerless and marginalised' groups challenged the expectation that they should be 'invisible and silent', they experienced 'surplus visibility'. This negated the dilemma of whether professionals were required to 'identify' disabled young people. For some young people with additional needs a choice of remaining unidentified amongst their peer group may be possible but the obvious nature of a physical impairment made this less likely. Thus these physically disabled participants may be especially vulnerable to risks associated with stigma, devaluation or rejection. Gaining the unique views of the young people themselves was essential to explore this issue further.

The curriculum dilemma may be appropriate for my participants but the assumption of a cognitive deficit due to the identification of a physical impairment was inappropriate. It may be the case, however, that an under-expectation of academic achievement by children with physical impairments occurred due to disabling views of non-disabled education professionals. (Oliver, 1996; Oliver & Barnes, 1998; Mason, 2008; Swain et al., 2003).

The placement dilemma was the key dilemma that my research explored in terms of the friendship opportunities and sense of belonging that physically disabled pupils experienced in mainstream and specialist settings. Is there a significant difference between the experience of mainstream or specialist setting experiences or are experiences wholly individual? I began this study by asking some of my participants if they preferred to be referred to as a 'disabled' or as a 'young person with a physical impairment'. All those asked said they preferred 'disabled' rather than 'impaired'. Recognising the 'child first' argument to labelling I began my research describing 'children with a physical disability' but as I researched the issue of medical and social models of disability I realised that the disability 'belongs' to society *not* to the young person and, therefore, in respect of the preference expressed by the young participants themselves I have chosen the 'disabled young person' label as most appropriate.

### **The medical or social model debate**

The 2001 Special Educational Needs and Disability Act was a positive linking of Special Educational Needs (SEN) with disability issues and Armstrong (2005) suggested this had been argued for by the Disabled People's Movement for many years but had often been ignored by politicians and professional agencies working with young people in educational settings (Oliver, 1996; Barton & Oliver, 1997; Oliver & Barnes, 1998). The Equality Act (2010) continues to describe disability in terms of an individual medical

model rather than social model despite the social model having been promoted by disabled people themselves for many years. For example Oliver (1996), a leading disabled researcher, outlined the differences between the two models of disability in Table 1.

Table 1. Disability models (Oliver, 1996, p.34)

<b>The individual model</b>	<b>The social model</b>
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalisation	Self-help
Professional dominance	Individual and collective responsibility
Expertise	Experience
Adjustment	Affirmation
Individual identity	Collective identity
Prejudice	Discrimination
Attitudes	Behaviour
Care	Rights
Control	Choice
Policy	Politics
Individual adaptation	Social change

The weakness, therefore, of continuing government legislation was that whilst it acknowledged inclusion, children's views being heard and their right to participation, it failed to fully acknowledge the political and social contributors to exclusion such as poverty, class and disability discrimination that may limit children's experience of equality and

inclusion. This was unhelpful as it encouraged the acceptance of SEN and disability as a 'within child' problem rather than looking at the systemic nature of a culture that labels certain young people as 'special'. Those that do not fit the norms of the culture are viewed as problematic rather than true embracing and valuing of human diversity (Billington & Pomerantz, 2004; O'Hanlon, 2003; Patai, 1992).

Consequently despite the positive steps towards inclusion that this and subsequent legislation offered, it remains essential for the Educational Psychologist (EP) to have a wider understanding of the socially constructed nature of Disability and SEN, that it is created by the social relations and power structures in society, in order to inform their research and practice more thoroughly (Oliver, 1996; Oliver & Barnes, 1998; Rustemier, 2002; Swain et al., 2003).

### **Teaching Assistants**

Recent government documentation (DfEE, 2000; DfES, 2004a; DfES, 2005a) also recognised the significant role played by Teaching Assistants (TAs) in the lives of children with additional needs. Yet many TAs experience a lack of clarity and training in the nature of their role and responsibilities. The Lamb Inquiry (2009) suggested that the Training and Development Agency for Schools (TDA) develop guidance on the effective deployment of teaching assistants (recommendation 5). This advocated that the role and best practice for TAs remains an area for development. Gerschel (2005) described the traditional role of the TA when supporting children with

additional needs as the 'Velcro model', that is, a TA attached to a single student.

### **Friendship and belonging**

TAs as well as teachers, therefore, required a range of skills to successfully facilitate friendship and belonging within schools. Gilligan (2000) suggested the qualities of engagement, responsiveness, humour and reciprocity are characteristics of 'resilience'. Building successful relationships in schools requires the young disabled person, their teachers, TAs and friends to possess all these qualities in a range of formal and informal contexts. The EP or TEP has a role in helping to support the building of these relationships thus ensuring more positive outcomes for the child (DfES, 2004a; DfES, 2004b). If we facilitate resilience by respecting and work positively with others, even when conditions may be stressful and parties feel distressed or vulnerable, then we create positive working relationships. Skilful listening and talking or effective communication Faber and Mazlish (2001) are an essential part of the toolkit of the EP that should not be underestimated. These skills enabled all parties to develop their 'vital senses of belonging, of mattering, of counting,' Gilligan (2000) suggested and this also upholds the ECM outcomes of health, safety, enjoyment and achievement (DfES, 2004b).

EPs have an important role in facilitating the four areas of development (emotional and social, cognition and learning, interaction and

communication and physical and sensory) outlined in the Code of Practice (DfES, 2001c). It is useful, therefore, to still recognise the value of Maslow's (1954) Hierarchy of Needs which featured belonging and esteem needs, including friendship, in our role to clarify needs and provisions for children. Gilligan (2000) also acknowledged the importance of peer relationships in helping all children develop emotional and social stability. He proposed a sense of belonging and self-efficacy were a protective factor against isolation and depression. Tashie, Shapiro-Barnard and Rosetti (2006) confirmed that the role of friendship is significant for young people and proposed that the most important factor in a child's happiness at school may be the quality of relationship they experience with peers. They argued that unless children with SEN's friendships are pro-actively facilitated by a change in attitude that encompasses their unique value and contribution to their schools and wider communities the practice of successful social inclusion will remain theoretical rather than actual.

## **Research aims**

The purpose of this study in paper one was to demonstrate a deeper understanding that eliciting young people's views and encouraging participation was not only consistent with espoused government and service aims but can be achieved in meaningful ways. In order to explore the understanding and meanings disabled young people accorded to friendship and a sense of belonging, and the importance of this for their

successful social inclusion, my research addressed the following research questions.

1. What opportunities do physically disabled young people feel they have to make positive relationships with adults and peers in mainstream or specialised settings?
2. Why are friendship and a sense of belonging important for physically disabled young people?

Findings from these questions were considered an important contribution to knowledge in their own right but also directly supported the investigation of the third research question that is explored in paper two.

3. How can we, as educational professionals, learn from the 'autobiographical voice' of disabled young people to improve the development of their friendships and sense of belonging to enhance their experience of social inclusion?



## Research design and methods

The methodology for this research project lies within an epistemology of social constructionism which asserted that people construct their own reality rather than there being one objective truth. This research design was hermeneutic in nature and, therefore, sought to recognise the lived reality of individuals rather than define general laws (Crotty, 1998). This acknowledged that disability is in many senses a social construction and that successful social inclusion, therefore, needs to be created rather than assumed by physical inclusion. (Fredrikson & Cline, 2002; Llewellyn, 2001).

Graue and Walsh (1998) recognised the validity and advantages of interpretive research using a 'grounded theory' approach but acknowledged this should be flexible. The fluid and changing nature of a child's friendships and relationships also required this flexibility. The small-scale nature of this study required an adapted methodology employing the principles of grounded theory and acknowledging the validity of the social constructionist approach (Charmaz, 2006, 2008). This accorded with the child competent and ethically respectful stance that I took with my research. This method, therefore, was appropriate for my ontological stance that young peoples' own views should be privileged as offering insight into the meanings they have created from their lived experiences. A systematic set of set of procedures were used, however, to develop an

inductively derived theory (Strauss & Corbin, 1990) from the expressed views of the participants.

The research questions were developed through interactions and discussion with disabled young people. I interviewed focus groups of disabled young people in specialist and mainstream settings to develop these questions further to create the interview schedules and questionnaires (see Appendices 7 and 8, p.154-157). I also asked the young people what further questions *they* felt adults should be asking disabled young people.

I was aware that as a non-disabled adult my research was concerned with understanding the views of disabled young people. I was conscious, therefore, of my subjective bias due to my difference from my participants. I was, nevertheless, able to draw on my previous experience as the daughter of a disabled man and as an advocate and ally of disabled young people both personally and professionally in my previous careers as a teacher and counsellor.

### **Participants**

My participants were a purposive sample of fourteen physically disabled young people aged between thirteen and seventeen years. All lived in the Southwest of England and attended full-time secondary education. Seven participants attended a specialist school and seven attended one of three mainstream secondary schools. Six participants were female and eight

were male. In order to ensure participants were truly anonymous I asked each participant to choose a 'name' so that no real names appear. School names have also been changed. I refer to this research as taking place in the Southwest of England rather than being more specific due to the particular identifiability of participants and settings.

Table 2. Participants

<b>'name'</b>	<b>Specialist School setting 'Lakeside'</b>	<b>Age</b>	<b>Brief biographical notes agreed with participants</b>
<b>Michael</b>		<b>14</b>	Michael has a lovely sense of humour and is best friends with Rose. She is a Michael Jackson fan!
<b>Elvis</b>		<b>15</b>	Elvis has complex needs and is friends with 'everyone'. He likes ICT and to be on school council so he can tell the teachers off sometimes.
<b>Rose</b>		<b>16</b>	Rose has a physical impairment and some medical and sensory needs. She is best friends with Michael and Robbie and likes horse riding.
<b>Jemma</b>		<b>14</b>	Jemma has a digestive disorder and is friends with Wendy. She likes school and all her TAs and stays at school during the week.
<b>Wendy</b>		<b>15</b>	Wendy has cerebral palsy which also affects her speech. She is friends with Jemma. She likes being friends with people.
<b>Robbie</b>		<b>16</b>	Robbie is a 16 year-old boy with a severe spinal impairment and limited use of one hand. He is the brother of James, is very good friends with Rose and likes quadbiking.
<b>James</b>		<b>16</b>	James has cerebral palsy and uses assisted communication and an electric wheelchair. He thinks James Bond is great and he is the brother of Robbie.

<b>'name'</b>	<b>Mainstream School setting</b>	<b>Age</b>	<b>Brief biographical notes agreed with participants</b>
	<b>'Elmside'</b>		
<b>Billy</b>		<b>13</b>	Billy likes school and football and has lots of friends.
<b>Chris</b>		<b>17</b>	Chris is a young person with severe arthritis. He often uses a wheelchair due to pain and fatigue. He plays wheelchair tennis and describes himself as very sociable.
<b>Jo</b>		<b>13</b>	Jo has no lower limbs below the knees and has an impairment of her hands. She loves swimming and wheelchair tennis and is very sociable. She is good friends with Lara.
<b>Lara</b>		<b>17</b>	Lara has cerebral palsy and some visual impairment. She has been educated in mainstream settings throughout her education. Lara describes herself as very sociable and was keen to talk about her experiences of friendship in the schools she had attended. She is good friends with Jo and loves dancing.
<b>'name'</b>	<b>Mainstream School setting</b>	<b>Age</b>	<b>Brief biographical notes agreed with participants</b>
	<b>'Riverway'</b>		
<b>Jackie</b>		<b>16</b>	Jackie has cerebral palsy and visual impairment. Jackie uses an electric wheelchair and has some control over her left hand but is unable to walk with a frame. Jackie has attended specialist and mainstream in primary school and is solely in mainstream at secondary school. She is unhappy with her relationship with her TAs and does not feel she has many friends at school. Jackie has one disabled and one non-disabled sister.

'name'	Mainstream School setting  'Uplands'	Age	Brief biographical notes agreed with participants
<b>Rocco</b>		<b>14</b>	Rocco has complex medical needs and walks with a limp. He describes himself as one of the 'cool ones' and likes to wear designer clothes. He is very independent and makes good use of his free bus pass.
<b>Keira</b>		<b>17</b>	Keira has cerebral palsy and has been educated in mainstream settings throughout her education. She uses a walking frame in preference to a wheelchair even though this is very tiring for her. She is very determined to access all areas of the school. She likes to change her hair colour frequently and wear 'cool' clothes. She is very reflective and reads extensively for pleasure.

The additional ethical consideration of having child participants especially those with additional needs were thoroughly considered and I fully complied with the ethical code of Practice of the British Psychological Society (BPS), gained consent from the University of Exeter research ethics committee, all participants and their parents (see Appendices 14 and 15 p. 177-180).

## Measures

Semi-structured interviews were recorded, transcribed verbatim and analysed using NVIVO and data coded and categorised with the focus on creating conceptual frameworks or theories through building inductive analysis from the data. Charmaz (2006) suggested that the analytic categories were directly 'grounded' in the data which favoured new categories over pre-conceived ideas and 'extant' theories.

Data was analysed for emergent codes and themes by constant comparison categorisation that were used to develop a conceptual framework. The transcripts were read several times to gain an overall view of the data and then analysed using NVIVO with a line by-line initial coding to allow accurate scrutiny of the data (initial codes). A more selective coding (focused code) was applied to the data which allowed me to recognise recurring patterns or themes in the data Charmaz (2008). These categories were refined into more conceptual categories (final code) allowing the main concepts of the young people's views to emerge.

My methods also included a small amount of subjective quantitative data within an interpretive framework using a simple rating-scale questionnaire developed from listening to the views expressed in the focus groups. This asked participants to rate their feelings about of their school lives and took place after the first semi-structured interview (see Appendix 8, p.157).

## Procedures and ethical practices

Focus groups were arranged in Elmside and Lakeside. We discussed the aims of my research, informed consent and I asked for suggestions of what questions adults should be asking young people about friendship and belonging in school. Those who wished to participate further were then seen individually on two to four occasions using semi-structured interviews. All participants were shown the vignettes, model of inclusion 1 and asked again for their consent before the action research group stage.

I remained aware throughout my research that as a non-disabled adult professional and researcher there existed a power differential between myself and my participants. I took time when I met with my participants to ensure that they understood the aims and purposes of my research, the concept of informed consent and that they and their parents knew they had the opportunity to withdraw consent at any time during the research. I emphasised that I was interested in their *real* views and that there were no right or wrong answers to any of the questions. I spent time building rapport with each of my participants and ensured they felt at ease with me and able to ask me to explain, repeat or not answer any of the questions.

For examples of letters explaining aims and purposes and consent forms see Appendices 15 and 16, p.177-184. I asked child participants for their written informed consent as well as adults as this was congruent with my ethical stance on children's voice, competency and rights.

# Results

My findings relate specifically to my first two research questions.

1. What opportunities do physically disabled young people feel they have to make positive relationships with adults and peers in mainstream or specialised settings?
2. Why are friendship and a sense of belonging important for physically disabled young people?

## **1. Opportunities for positive relationships**

The semi-structured interviews elicited a wide range of views and covered aspects such as the school environment (special rooms, lifts, stairs, corridors and doors); making and sustaining friendships in and out of school (disability sports, social networking, dance and drama) and the role of TAs in facilitating or creating barriers to friendship.

The example of coding below uses a methodology that was adapted from Charmaz (2008). I used Nvivo software on the full transcripts of each semi-structured interview. I began with a systematic initial line-by-line coding which I then re-examined to focus on the main themes that were emergent. These themes were finally distilled further into discrete conceptual categories.



## Social space and time at lunch and breaks

Table 3. An example of comparison of category coding of semi-structured interviews

Final code (Conceptual category)	Focused coding	Initial coding: (line-by-line)	Data
Surplus visibility	Not able to be 'under the radar' - Velcro model	TAs like glue, friends aren't allowed	<p><b><u>Lara: Elmside (mainstream)</u></b></p> <p><i>"At the other school it was really different I had much less friends there. My TAs stuck to me like glue. They were control freaks and wouldn't let me hang out with my friends. They used to make me go to room 10 and then 1 TA could look after all the kids with SEN but they wouldn't let my friends come in most of the time. They wanted me to stay in room 10 cos they were over-protective but I wanted to be with my friends. It was very difficult. Here, room 57 is way better, my friends can hang out with me.</i></p> <p><i>I can invite who I like to room 57. We don't let it get too overcrowded, a sensible amount is allowed. If it gets too crowded then we can ask some to leave or Bridget will just come in and kick some out which is quite funny. She'll just check how many's there and what they're behaving like. Just general anyway. So there's no TA there all the time which gives us a lot of independence which is really, really good. Yeah we get a helluva lot of independence whereas as in room 10 at my last school we were being monitored, we were being watched, we were being told what to do, our friends weren't allowed in, so basically they were controlling us."</i></p>
Friendship	Barriers to friends	TAs in control	
Power	Child deficit model	'SEN' room	
Choice	A real social space	Over-protective	
Competency	Child capable	Pupils regulate as well as TAs	
Lack of Agency	Friendships	Like the room/can have friends there	
	Adult control	Independence	
		being watched and monitored	

Final code (Conceptual category)	Focused coding	Initial coding: (line-by-line)	Data
<p>Competency</p> <p>Privacy and autonomy</p> <p>Fun and Intimacy.</p>	<p>Environmental barriers</p> <p>Finds a way to share social time with friends</p>	<p>Meets up with friends</p> <p>No special room</p> <p>Share private thoughts and jokes</p>	<p><b>Michael:</b> Lakeside (specialist)</p> <p><i>"I walk around at lunchtime with Rose and Danni.</i></p> <p><i>We don't go out or have a room we walk along the corridors.</i></p> <p><i>We have a laugh."</i></p>
<p>Friendship and Belonging</p> <p>Autonomy and choice</p> <p>Choice to be social or private</p> <p>Agency</p>	<p>Social relationships expected</p> <p>Communication with peers</p> <p>Choice of environments</p> <p>Warm environment</p>	<p>Socialising at school and home</p> <p>Choosing the room to be with friends.</p> <p>Use of common room to read or work</p> <p>Choice of rooms</p> <p>Somewhere warm</p>	<p><b>Keira:</b> Uplands (mainstream)</p> <p><i>"I feel like I can socialise in school as well as home. Especially in the 6th form, you know, you sit in the common room, you talk to people.</i></p> <p><i>Most of the time I go to learning support actually, but that's just because most of my friends go in there, but I do go in the common room, especially when I've got like study periods.</i></p> <p><i>I tend to sort of drift over there and just sit and read a book or do some work</i></p> <p><i>There isn't an allocated room for any specific person or tutor, I think there's a tutor room which you can have your lunch in, but no, it's always generally been learning support or sitting somewhere else.</i></p> <p><i>It's nice and warm in there too. That's all that gets me, is the warmth.</i></p>

Final code (Conceptual category)	Focused coding	Initial coding: (line-by-line)	Data
Physical needs    Lack of Autonomy/ Privacy Feelings	Physical and medical needs prioritised  Friendship barriers  Frustration  Isolation  Feelings of annoyance	Being cared for  Care workers as barrier to friends  Loss of friends  Friends avoid TA mediated conversations	<b>Jackie:</b> Riverway (mainstream)  <i>The TAs have breaks but some of us need, well most of us are, need health care assistants, but just like fulltime care, which means that after the TAs go, the people who are holding your lunch are there, so you can't really have any kind of serious conversation and it's kind of in a weird way like losing my friends, because they think, 'oh, her TA will just get involved anyway, so there's no point in talking to her'. And I'm like, 'but my TAs aren't speaking for me' but they're like, 'your TAs always talk anyway, so we won't talk to you for breaks and lunch'. So I'm on my own really. That's why I'm always quite, I always like have this face on, because I'm annoyed. I don't feel great.</i>

This coding revealed that despite the similarity that Lara, Keira and Jackie all have cerebral palsy they had very different experiences of being able to occupy a social space at break and lunch times. Lara contrasted a previous negative mainstream experience with a present positive experience. Keira talked positively about being able to choose a range of rooms. Jackie had very negative feelings about carers and TAs being a barrier to friendship

and throughout her semi-structured interviews the theme of no choice re-occurred. In the scaled questionnaire Jackie rated herself as 'excluded' and 'don't feel valued' which supported the data gathered in the semi-structured interviews.

Concepts such as choice, independence, friendship, agency and power emerged. The concept of choice was a key and occurred frequently both within interview data of individual participants and between participants.

*"That's where the TAs put us 'cos it's convenient for them. It's not where anyone would decide. They put us with other disabled people."*

(Jackie, 16, Riverway)

### **Friendship through sporting and social activities in school and wider community**

Chris, Lara, Jo and Rocco all spoke in detail about meeting and gaining friends through disability sports, drama and dance and social networking. See Appendix 10, p.159 for an example of concept coding from Chris's semi-structured interview data.

Chris's experience contrasts with that of most of the children from special schools who reported very little socialising outside of school despite the fact that in many cases their physical impairments were at a similar or

lesser level than Chris's or others in mainstream settings. The building of confidence through wheelchair tennis and the social life this enabled were significant factors in Chris feeling a sense of social belonging in the wider community and not just to school.

### **Social networking**

The use of social networking was revealed by participants as a way of keeping in touch with friends out of school. Most of the mainstream participants used the Internet for social networking but none of the Lakeside participants did this and the following participant, 'Rose' was very unsure of her permission to email her school friends (see Appendix 3, p.150).

Social networking is another opportunity for disabled young people to connect with others without it being monitored or censored by adult views but parents and some pupils are reluctant to make use of these opportunities due to fears about grooming and cyber bullying. Some of the disabled young people don't have the personal confidence or sense of their own agency to make this happen even although they have the technical skills needed.

*Interviewer: So can you email at the moment?*

*Rose: I've got my own email address but I don't know my best friends Jenny and Lucy's. I mean I would like permission to know their email*

*address...and probably Jenny and Lucy might need permission from their parents as well, to see if they can give me the email address.*

(Rose, 16, Lakeside)

So although Jenny and Lucy are Rose's best friends and she is about to leave the school Rose at sixteen doesn't know their email addresses and feels she needs to ask 'permission' from adults for this rather than just negotiate it with her friends.

## **2. Reasons for the importance of friendship**

All participants without exception stated that friendship was very important to them. This was equally true of male and female participants and also supported by the quantitative data.

The initial codes for the answers given to this question were 'gentle intimacy' (from Robbie's tone as well as words spoken), 'sharing a joke', 'feeling secure' (Chris) 'helping to avoid and resolve bullying' (Billy), 'talking and helping' (Elvis), 'being social and TAs appreciating this as important' (Lara), 'trust and confidence', (Keira), 'rare and important to reduce loneliness', (Jackie), and looking out for each other', 'telling and solving our problems' (Rose) and these led to focused coding that included

intimacy, fun, security, capability, trust and confidence, isolation and exclusion.

See Appendix 11, p.160 for verbatim data in response to the question, 'How important are friends to you?'

Examples include:

*"A lot, very important. Well me and Rose are just really good friends, and it's really, really lovely, yeah."* (Robbie, 16, Lakeside)

*"Socially it means a lot to me. I get on well with everyone so even if you don't like the lesson when you've got a group of friends that you know you can sit there with and joke about with and have a good time in the lessons as well as learning stuff. ..(Chris, 17, Elmside)*

*"Important because if you're like bullied they can help you out of it. Yea, my friends like helped me out of it...this boy kept on annoying me ...my friends actually said something to him and then he like stopped. And me and the boy actually made friends and we're still friends."* (Billy, 13, Elmside.)

*"Very, very important. I just make sure I always have friends with me! I like to be very social and the TAs realise this and they realise it's important they get along with my friends too."* (Lara 17, Elmside)

*"The ones I have and the ones I find it quite strenuous to keep are really quite important, because I have so little anyway, I only have like one here that if I don't keep that one, I'll be alone again I suppose."* ( Jackie, 16, Riverway)

*“Very important to me ...because we’re best friends and we look out for each other and we stick up for each other as well. And if someone is worried... what’s on their mind and what’s the problems ...then we get over it together.” (Rose, 16, Lakeside)*

Grounded theorists initially concerned themselves with the categories or concepts that they inductively developed from their data but Charmaz (2008) reveals that she likes to present many detailed interview quotations. As I am particularly concerned with giving my participants opportunity for their ‘voice’ to be heard I have also chosen to do this. Nevertheless I recognise this is a selective process and due to word limitations I have necessarily privileged certain quotations from the data set.

An analysis of the qualitative data gathered from the complete data set, however, revealed the following as final core concepts that were inductively developed from successive coded analysis.

- Surplus visibility,
- Friendship, Fun, Belonging,
- Power, Trust
- Autonomy, choice
- Agency , Competency,
- Feelings, Isolation, Intimacy, Privacy,

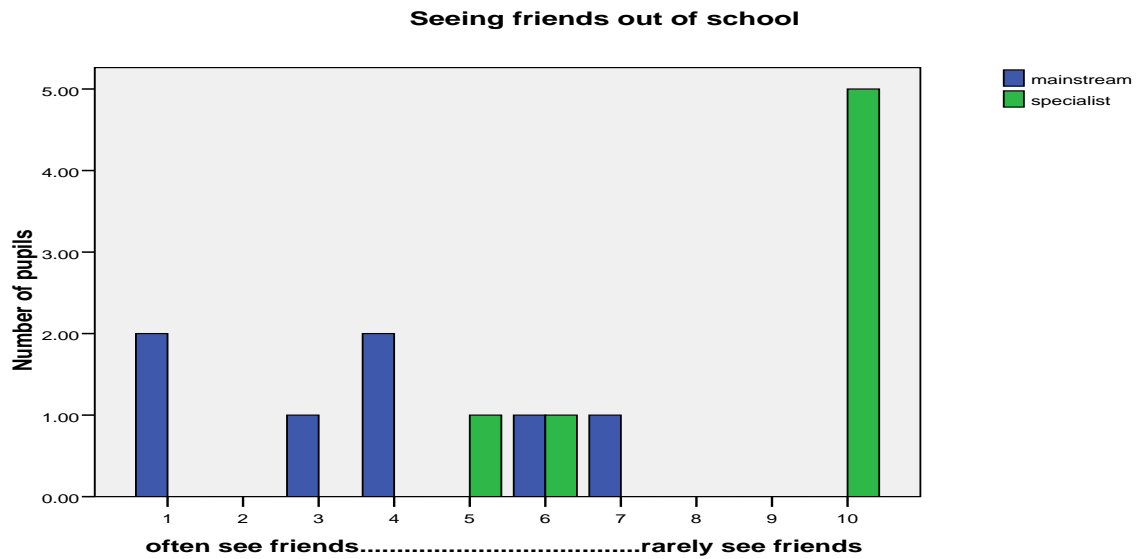


- Confidence, Opportunity, Empowerment
- Rights, Responsibilities
- Access

In order to offer a small amount of subjective quantitative data to contribute to answering the research questions all participants were asked to complete a simple scale-type questionnaire (see Appendix 8, p.157). This data is collected, therefore, within an interpretive framework and represents the participants' personal views. The graphs show where the participants placed themselves on a scale of 1 to 10. The participants have been categorised in two different ways, by school setting and by gender, in order to notice any patterns that emerge from the data but all participants are seen as individuals with unique personal perspectives for the purposes of this research and it is not intended that they should be assumed as a homogenous group of mainstream or specialist pupils. The value of the scale for this research is that it aided my focus for subsequent interviews. (see Appendix 12, p. 161-166 for graphs and comments).

See Figure 1. for a graph that captures and supports a key finding from qualitative data.

Figure 1. Graph showing participants' perceptions of frequency of seeing friends out of school.



Seeing friends out of school showed the biggest difference of the questionnaire between the mainstream and the Lakeside participants in that 5 out of 7 Lakeside participants rated themselves 10 out of 10 as rarely seeing friends out of school and no mainstream pupils rated themselves as rarely seeing friends out of school. There were no significant differences between male and female participants.

## Discussion

The aims of my study were met by the clear voices of the participants which allowed for a depth of understanding that disabled young people placed a great importance on friendship which was a significant factor in their happiness and sense of belonging. The discussion is organised by a selection of themes that have emerged from my key findings

### Choice, friendship and belonging

The findings revealed the importance that disabled young people placed on having a space that is theirs, not adults, to spend their break and lunch times with chosen friends. This supported the concept that young disabled people need a voice and a choice about their social inclusion in schools.

Cook et al. (2001) recognised,

*“much of the research on disability, including disabled children, has ignored the views and experiences of disabled people themselves.”* (p.24, 2001)

If we ignore the voice of disabled young people as EPs and researchers we are in danger of replicating the experience of young people like Lara and Jackie who have felt unheard by their schools

*“That’s where the TAs put us...slap bang in the middle...‘Cos it’s convenient for them. It’s not where anyone would want to sit, it’s*

*just where they like decide'... They put us with other disabled people." (Jackie, 16, Riverway )*

Being 'parked' in the middle of the dining hall with the group of wheelchair users was seen by participants as inappropriate and distressing as was being expected to use the SEN room without the opportunity to invite their actual friends to share this space. On both occasions when Jackie and Lara with cerebral palsy expressed their views to TAs that they did not want to be 'placed' where the TAs had decided they were safe or 'among friends' their views were discounted and they were told to remain there anyway.

### **Feelings: Fun, intimacy and privacy**

Some of the most successful rooms were not necessarily the most attractive or well resourced but were where teachers and TAs understood and respected the young people's rights and competency to manage their own space and choice of friends with minimal adult supervision. So this space need not be well equipped but should be '*our space*', '*warm*' and free to include non-disabled as well as disabled young people. The participants wanted a space where they could be free to have fun or share private conversations with their friends. Also an environment that was warm was raised by participants as although they managed pain and fatigue with minimal assistance from adults they appreciated an environment that was sensitive to their needs (Crow, 1996). Students did

not want this drawn attention to, however, just facilitated by an environment that was warm and where blankets and hot grain-bags were available with ease. This was managed well in most of the schools where SENCos and TAs were seen as *'in tune'* with the needs of disabled pupils.

Whilst the participants were comfortable with the presence of adults they felt most included and valued when they were trusted and judged competent to oversee the presence, numbers and behaviour of their friends themselves.

*"We don't let it get too overcrowded, a sensible amount is allowed...So there's no TA there all the time which gives us a lot of independence which is really, really good. Yeah we get a helluva lot of independence."* (Lara,17, Elmside)

This is a clear message that trusting in a young person's competence is an integral part of them being able to develop those skills and competencies with the support of friends. This contrasts with an earlier experience of a different school for Lara,

*"In room 10 at my last school we were being monitored, we were being watched, we were being told what to do, our friends weren't allowed in, so basically they were controlling us."* (Lara,17, Elmside)

## Surplus visibility

The opportunity to be 'off-task' to be 'naughty', to dissent, to '*get away with it*', to choose who you want to be friends with and who you don't.....this is everyday yet denied to many disabled young people. Private intimate conversations with friends can be thwarted by well-intentioned TAs who are over-protective. Down time, off-task time may also be denied and it is these times when friendships are formed. The idea of TAs as barriers rather than facilitators of friendship occurs throughout the semi-structured interviews of Jackie and occasionally in Lara, Michael and Rose.

Patai's (1992) concept of 'surplus visibility' is illuminative in these views, that when 'powerless and marginalized groups challenge the expectation that they should be 'invisible and silent', they experience 'surplus visibility'. In this way Jackie, and other disabled young people, are required to

*“choose between invisibility and surplus visibility, between silence and the accusation that they are making excessive noise. Surplus visibility reinforces the invisibility imposed on the marginalized by making it safer to go one's own way quietly, without calling attention to oneself.”*

(Patai, 1992, p.35)

Primarily used in discussion of discrimination towards 'racial and ethnic minorities' this concept also has particular salience for disabled young people. For those of us used to being in positions of privilege or power, for example, the non-disabled or perhaps even adults, any space that 'minorities' occupy Patai (1992) argued appears excessive and the voices 'they' raise are viewed as loud and offensive. This echoes Jackie's view that she was required to be excessively polite and grateful to her TAs and was seen as *'rude'* when she believed she was just being a *'normal teenager'*. Billington and Pomerantz (2004) agreed that people see this as norm violating behavior when it was often a response to a lack of being listened to leading to low morale and hopelessness. Jackie's interviews confirmed that she did experience low morale due to not being listened to.

An understanding of disabling attitudes and sensitivity on an individual basis was needed to ensure that disabled young people were not 'parked' in the middle of a room or highlighted as different by obtrusive overly overt differentiation. This confirmed that their voices and preferences needed to be sought and acted upon rather than assumptions made by adults.

The issue of 'difficult difference' was explored by Rogers (2007) who contends that difference may be unwelcome to society but if the child's difference is also 'difficult', in the sense of anti-social behaviour or distressing visual presentation, then society may be even less inclined to be

accepting or including. This conversely may mean that well-intentioned but perhaps 'adultcentric' (Matusov & Hayes, 2000) TAs decide that disabled young people in their care like Jackie who have 'surplus visibility' in terms of being wheelchair users should be placed in a group of similarly disabled young people with an assumption that this is better for them than being included in with their classmates. This highlights Oliver's (1996) view of the 'problematic' nature of inclusion that even when children are physically included in a school or judged to be appropriately placed in a peer group this can feel acutely distressing to the young person if their views are not sought or are actively discounted.

The assumption that non-disabled young people would rather exclude visibly disabled young people, however, was contradicted by my findings when young people themselves have autonomy and choice within their friendship groups they chose their friends among peers they like for '*fun*', common interests and '*easiness*' and not necessarily for similarity of impairment or need.

Shakespeare and Watson's (1998) suggested that children can have profound experiences of life, including disability, but have not been consulted or taken seriously by academic or professional 'experts.' This is a valuable area for further research as my findings confirmed that disabled young people can not only express their views but can do so in articulate



and deeply powerful language which requires us as EPs and allied professionals to find the will and time to listen to what young people want to tell us.

## **Access**

Physical access to lifts, ramps, and open able doors were valued by Jo, Chris, Lara and Keira. The quality of staircases as *'not too open and scary'* was also highlighted by Rose. One of the ways in which these pupils felt valued by their schools was the attention and quick resolution given to problems like broken lifts as they felt this fully acknowledged their needs and rights to access all their classes. It was noted and disliked by Chris and Lara when this had not happened in previous schools or buildings had been inaccessible as this was seen as excluding and devaluing. The issue of safety arose in mainstream and specialist settings with safety being raised frequently as an important issue in specialist settings by Rose, Elvis, Wendy and Michel to want to feel *'safe'*, secure and *'happy'*. Safety issues were sometimes seen as deliberate barriers constructed by the TA for their convenience rather than the young person's by Lara and Jackie. This was described in terms of an *'over-protectiveness'* and an *'over-anxiety'* in mainstream settings and this raised barriers to inclusion and to developing friendships.

## **TAs: A central role**

TAs, however, were often spoken of with affection by Lara, Rocco, Rose and Robbie but were occasionally seen as barriers to friendship with peers. Jackie spoke about her difficulty in making real friendships in mainstream and expressed the view that, as well as the physical barrier of a wheelchair TAs also acted as a physical and social barrier between her and her peer group as they sat between her and friends and often spoke 'for' her ,

*“so you can't really have any kind of serious conversation and it's kind of in a weird way losing my friends, because they think, 'oh, her TA will just get involved anyway, so there's no point in talking to her'. And I'm like, 'but my TAs aren't speaking for me' but they're like, 'your TAs always talk anyway, so we won't talk to you for breaks and lunch'. I'm on my own really.” (Jackie, 16, Riverway)*

In Lakeside the participants accepted the lack of a social room and Rose and Michael used the corridors to manage conversation time that was peer only and not overheard or mediated by TAs. Jackie was the only participant to be feeling unhappy about her TAs at the time of interviews and she is now delighted to be moving to a different school for her post-16 education. Other mainstream participants developed very positive relationships with their TAs but Lara also changed school post-16 partly due to these relationships being problematic. Previous TAs were described

as 'over-protective', 'controlling', 'stuck like glue', 'breathing down my neck'.

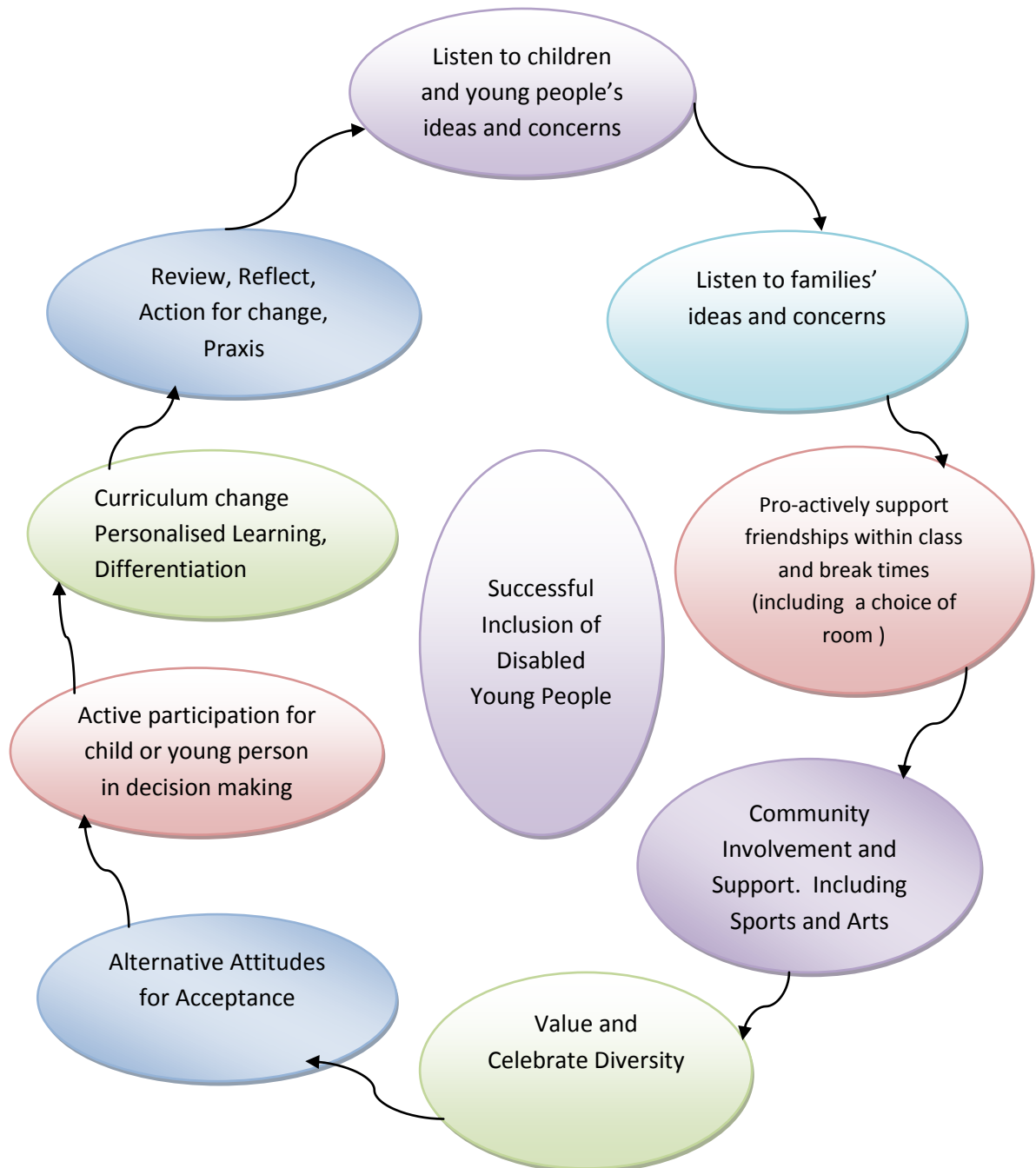
Lakeside participants were more accepting of the omnipresence of TAs but Elvis also expressed the desire that the TAs should at times be '*away from me and not right next to me*'. This supports Gerschel's (2005) findings of the problematic nature of the 'velcro' model of the TA but again the variety of responses would suggest that disabled young people have complex individual attitudes to their TAs based on the quality of their personal relationships. Many pupil's genuinely regarded some of their TAs as valuable and '*fun friends*' and the sensitivity of the TA in knowing when to be out of the young person's personal space at social times in class or breaks was appreciated. This raises the issue of the quality of training, recruitment, pay and conditions for TAs who play a pivotal role in the school lives of many disabled young people. I believe the EP could be a valuable resource for school's for TA training.

### **Methodological successes and constraints**

This model for social inclusion is developed from the grounded theory methodology of analysis of disabled young people's views. It offers a valuable starting place for schools to reflect on how pro-active they are being in terms of social inclusion. The disabled young people had a generally positive reaction to this model when shown it in our final meeting and were happy for it to be used

alongside vignettes of their views in the action research groups that form the next stage of this small-scale study.

Figure 2. Social inclusion model 1



The limited time scale and word constraints of this small-scale study necessitated a simplified adapted grounded theory methodology but I believe it has successfully met the aims of this study allowing an ethical and

authentic account of children's views to be privileged. As a non-disabled adult it would be tempting for me to reframe participants' views in terms of good intentions by adult TAs but it is essential that I accept authentic views. It is acknowledged that these views are the lived reality of my participants in this particular time and context and do not represent a generalisable truth. The opportunities, however, for further insight, reflection and later praxis that active listening to these young people offered a more sensitive understanding to evolve and be embedded in EP practice. Charmaz (2006) asserted that theory developing from grounded theory is valid and useful and can be appropriately utilised in conjunction with action research. In the second part of this small-scale study I hope to demonstrate that active involvement in action research can also be useful and empowering for all participants.

## **Conclusion**

This research has found that the dilemma of successful inclusion for all young people moves beyond a simplistic notion of physical inclusion in mainstream settings being unproblematic (Oliver, 1996; Thomas & Vaughan, 2004). A respectful understanding of the value of the physically disabled child as a vibrant and important part of the diversity of human beings is recognised and celebrated in this study.

By actively listening to the views of physically disabled young people the importance of valuing and engaging pupils in making real choices about their friendships, environments and school experiences in a meaningful

and participatory way is actively acknowledged and acted upon. In order to empower young people we as professionals may have to relinquish some of our control and power and trust in the competence of the young people themselves to regulate and construct optimum inclusive environments. In order to offer insight and practical ways forward to promote participation of the young person in decision and school policy making we need to assist in further training for teachers and TAs in how to enable the young people to be heard and their own 'expert' views valued sufficiently. The model of inclusion I have offered is a starting point to facilitate a positive school culture where social inclusion is recognised as important and possible. When disabled young people are provided with the opportunity to exercise their agency, demonstrate their humour, skills and social competence through friendship and belonging then true social inclusion is more likely to occur in our schools.

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## **Paper Two**

**Authentic voices for action research engaging schools in change towards social inclusion.**



## **Abstract**

This small-scale study was positioned within a social constructionist interpretive paradigm using action research as a stimulus for school change towards greater social inclusion. Three schools took part, a specialist setting and two secondary mainstream settings.

Action research groups consisted of parents, teachers, Teaching Assistants (TAs), Special Educational Needs Coordinators (SENCOs), senior management and allied professionals. Groups met three times and the study was conducted over a four-month period.

The action research groups explored authentic views of young people represented in vignettes, discussions in groups, further discussions of participants with disabled young people, the development of conceptual maps, evaluation and change intentions.

This built on previous research by Barrett (2006) in which he used autobiographical accounts of young people with autism as stimulus for INSET discussions. Barrett's study was limited by the absence of views of actual pupils in the school and, therefore, unique insight into local and community contexts was lost.

Findings were that participants when talking directly to their own students and children discovered that assumptions they had made about key concepts such as friendship, choice and access to a suitable room at break time were not as expected. This encouraged reflection and a greater understanding of students' lived experience thus stimulating an intention to change practice to enhance social inclusion and further involve parents in this process.

## Introduction

The Salamanca Statement (UNESCO, 1994) recognised the importance of encouraging and facilitating the participation of parents and disabled people, their organisations and communities in the decision making processes concerning the provision for special educational needs. The second stage of my research, therefore, widened the participation in the research process to parents and a variety of school staff with the purpose of making changes to practice.

*“Moves towards inclusion must be founded on participative involvement of disabled people (adults and pupils) in changing education.”*

(Cook, Swain & French, 2001, p. 294)

## The context

As in paper one this second part of my study is also set in the context of a professed increasing government commitment to inclusion of pupils with physical disabilities in mainstream settings SEN Code of Practice (2001c), Disability Discrimination Act (2005), the Every Child Matters (ECM) agenda (2004b), Removing Barriers to Achievement (2004a). It also acknowledges a dilemma of schools' anxieties about league tables and results in the climate of a governmental raising standards agenda dissuading some schools from making the reasonable adjustment required for pupils to experience full

social inclusion (Thomas & Vaughan, 2004; Topping & Maloney, 2005; Norwich, 2008).

The Lamb Inquiry (2009) highlighted that parents experienced a lack of confidence in the education system in regard to providing for children with SEN. This stated that parents needed to be listened to more and the system needed to be more ambitious for their children. In order to respect parents' valuable contribution and bring about meaningful and appropriate changes in the lives of young disabled people in schools and wider community it is essential that parents are included as part of the process of inclusion. Lamb (2009) suggested there is a 'unique opportunity' to make a real and lasting change for children and young people now and in the future. He argued, however, that this will only be achieved if everyone 'within the system' worked towards this.

## **Rationale**

In order to make change, therefore, we need to recognise who is within the system and, in an echo of good inclusive practice, make every effort to draw parents, carers and para-professionals into the system. Hick (2005) recognised that whilst inclusive practice at an individual level may be well

established by EPs there was a further role in developing and promoting more inclusive whole school practice.

Government legislation (DfEE, 2000; DfES, 2004a; DfES, 2005a) also recognised the significant role played by TAs in the lives of children with additional needs. The young people I interviewed named TAs and friends as key people in their experience of school. Yet many TAs experience a lack of clarity and training in the nature of their role and responsibilities. The Lamb Inquiry (2009) suggested that the Training and Development Agency for Schools (TDA) develops guidance on the effective deployment of teaching assistants. This action research study explicitly addressed how TAs can be most effective in facilitating social inclusion and enabling friendships.

## **Selected literature and theoretical aspects**

### **System change**

I introduce a small sample of the literature on organisational change which informed my long term aims and expectations on what can be achieved with this action research project.

In order to facilitate and sustain change in the school system a more effective strategy than a one off INSET presentation may be required.

Georgiades and Phillimore (1975) examined the problems of relying on training as the main strategy for inducting organisational change. The authors drew on evidence to assert that attitudes developed in training are often not sustained in the workplace. They suggested that the greatest influence on behaviour is the leadership of the person's immediate supervisor. Therefore, I recognised the importance of engaging senior management and line managers, including SENCOs, as well as key people in young people's school day such as TAs, teachers and parents in this research.

In using action research as a method of encouraging practice change I was aware that through involving a representative from many aspects of the school community I was able to share ownership of the research process with key people in the life of disabled students. Fullan (2003) asserted the need to involve those with the power to make changes happen in school initiatives and this has many links to Georgiades and Phillimore (1975) who emphasised a need to work with groups within the system likely to be supportive of change and new ideas. It is useful to compare the similarities and differences between these authors of systemic change literature and I have captured the essence of this in Table 5.

Table 5. A Comparison between the myth of hero innovator and complex change lessons

<b>8 Complex Change Lessons</b> Fullan, 2003, p.24		<b>6 Guidelines for achieving change</b> Georgiades and Phillimore (1975)	
1	Give up the idea that the pace of change will slow down.	1	Change will take 3-5 yrs
2	Coherence making is a never ending proposition and is everyone's responsibility.	2	Work with individuals and groups that have the freedom and capacity to change.
3	Changing context is the focus.	3	build groups, not individuals working in isolation.
4	Premature clarity is a dangerous thing.	4	Avoid premature evaluation of the group
5	The public's thirst for transparency is irreversible.	5	No mention of public
6	You can't get large scale reform through bottom up strategies – but beware of the trap.	6	Ensure you have permission from top management and commitment from near the top management if possible.
7	Mobilize the social attractors – moral purpose, quality relationships, quality knowledge.	7	Work with the forces supporting change not those resisting it, that is, work with the healthy parts of the system
8	Charismatic leadership is negatively associated with sustainability.		Myth of the hero innovator

Georgiades and Phillimore (1975) offered six guidelines for achieving successful organisational change and it is useful to compare these with the '8 complex change lessons' formulated by Michael Fullan (2003) nearly three decades later. The similarities are clear with an exception being that

nearly thirty years ago there was little concept of transparency towards the public. Transparency now includes parents and their wish to be involved in their children's education, success and well-being. In this study parents were viewed as equal partners in the research and as having a valuable contribution to enhance social inclusion.

Another difference is rapid change rather than three to five years. The change in present society is imposed rapidly but sustainable change in the attitudes and practices of professionals may take time and remain at a slower pace.

Fullan (2003) advocated

- *Start with the notion of moral purpose, key problems, desirable directions,*
- *Create communities of interaction around these ideas.*
- *Ensure that quality information infuses interaction and related deliberations.*
- *Look for and extract promising patterns, that is, consolidate gains and build on them.*

(Fullan, 2003, p.23)

The moral purpose of this research was to enhance children's experience of friendship and belonging in order to ensure their successful social inclusion and happiness. This addressed the desired outcomes of the ECM



Agenda (2004), '*stay safe, be happy, enjoy and achieve, make a positive contribution*' directly. The key problem was how to do this or how to 'operationalise' these aims. Action research offered an ethical and effective way to create a small community of interaction to use the quality information of the findings including vignettes from the first part of the study. In looking for patterns between their students and original participants we 'consolidated gains and built on them'.

The role of the EP as 'critical friend' and a person 'meta' to the system with the ability to have both 'insider' and 'outsider' viewpoints may be especially useful in action research projects (Winter, 1989). Growing importance is placed on research as part of the role of the EP and, therefore, a consideration of what research is most useful and ethical to the young people, families and schools as well as to services is meaningful. The time limitations of this small-scale study meant that this action research is acknowledged as a useful beginning to further collaborative practice and research development within the schools. The action research consisted of three meetings in three schools over a four month period which was a short time span for such an undertaking. Dilts et al., (1990) suggested a small change in understanding or beliefs, however, brought about by involvement in the reflective process, remains of value. Thompson (2007) described change in schools as 'a complex and somewhat unstable notion' with no single recipe requires a combination of local action and outside support.

Involving parents as well as TAs, teachers and senior managers was a key decision that developed from my analysis of young people's views in the first part of my study and a growing awareness of the importance of including parents and listening to their views in regard to children with SEN (Lamb, 2009). I also recognised the capability and resilience of parents of disabled young people as well as the struggles they faced in a disabling society (Mason, 2008; Oliver, 1996; Rogers, 2007). This also countered the 'expert model' which positioned parents as passive recipients of professionals' knowledge and advice (Frederickson & Cline, 2002).

The thinking of the disability movement, disabled people's voices and the development of the social model as detailed in paper one are essential to the process of inclusion (Rieser, 2000). Inclusion in itself is a process of school change that benefits the entire school community. Oliver (1996) asserted the value of acknowledging that disability is a human rights issue and a fundamentally moral and political issue of integration or segregation that required people to broaden their outlook. See Table 6.

Table 6. Integration or inclusion Table (Oliver, 1996, p.84)

<b>Old views</b>	<b>New views</b>
1. State	1. Process
2. Non-problematic	2. Problematic
3. Professional and administrative approaches	3. Politics
4. Changes in school organisation	4. Changes in school ethos
5. Teachers acquire skill	5. Teachers acquire commitment
6. Curriculum delivery must change	6. Curriculum content must change
7. Legal rights to integration	7. Moral and political rights to integration
8. Acceptance and tolerance of young people with SEN	8. Valuing and celebration of young people with SEN
9. Normality	9. Difference
10. Integration can be delivered	10. Integration must be struggled for

The old and new views of inclusion expressed in Table 6. are relevant to the aims of both phases of my research. They are particularly useful to this second paper as they offer a new attitude and context for inclusion within which organisational change may be more likely to occur to achieve successful social inclusion.

### **Participation**

One of the themes emerging from the data of my first paper was a desire to be listened to and to participate in a wide range of school and social activities.

Hart's (1992) 'Ladder of Participation' clarified the degrees of non-participation (manipulation, decoration and tokenism) that have traditionally been experienced by children. Shier (2001) offered an alternative model of participation.

1. Children are listened to
2. Children are supported in expressing their views
3. Children's views are taken into account
4. Children are involved in decision-making processes
5. Children share power and responsibility for decision making processes

I recognised the validity to a commitment to all five levels as an ongoing process at the level of organisational change but I acknowledged the limitations of my own small-scale study in this respect.

## **Research Aims**

The specific aims of this action research project were to develop a shared understanding of how to promote the successful social inclusion of disabled young people. Young disabled people's authentic views from the findings of my first study, that is, views expressed directly by young people

themselves and not based on assumptions of what people think disabled young people want and new discoveries made by the action research participants in talking with students in their own schools and communities were a central part of this active process. The development of conceptual frameworks from these discussions were offered as stimulus for further development and change.

These processes address my final research question,

How can we, as educational professionals, learn from the 'autobiographical voice' of disabled young people to improve the development of their friendships and sense of belonging to enhance their experience of social inclusion?

## Design and Methods

For the second part of my study I used the views of the young disabled people on friendship and belonging, as a stimulus for action research to include reflections on practice and potential attitude or school change. This part of my research was also drawn from an epistemology which is broadly social constructionist. My theoretical perspective remains interpretive as I acknowledge that individual's construct meaning from their lived experiences.

This small-scale action research project raised awareness about inclusive educational practice at a local level to empower students, parents and professionals in a meaningful educational and community context. O'Hanlon (2003) proposed that action research is a dynamic process which speaks powerfully to the practice of the EP. It promotes collaborative working, recognises the strengths and rights of the research community, and recognises the potential for change in the development of relationships within groups of people. In this study the research community is considered to be the students whose views are sought, the parents and the school staff who participate in the action research, any other professionals who participate and myself, TEP researcher.

The decision to use action research as a methodology for the second part of this small-scale study was an acknowledgement that to bring about systemic change within organisations it is essential to work collaboratively and reflectively with colleagues and parents (Fullan, 2003).

This study is an intention towards praxis (Freire, 1972) where reflection and intention to action are both required in order to transform behaviour (Crotty, 1998). Therefore, the successful outcome of this research is also acknowledged as the value of the process of the action research for development of reflective practice leading to school change as well as the thematic analysis of data and the formulation of theory or conceptual frameworks.

Braun and Clarke (2006) suggested thematic analysis was a useful and flexible method for qualitative research in and beyond psychology which allows for 'complex and nuanced' analysis. They contested that its familiarity caused it to be overlooked as a foundational method of providing 'rich' data and capturing 'key' important themes. This method was compatible with constructionist paradigms and offered rich description of data which was both useful and authentic when researching an under-researched area or participants whose views were not known. It was, therefore, a valid and effective choice of method for this second part of the study.

## Participants

Participant groups were drawn from three different schools who had expressed an interest in social inclusion. All participants were voluntary and had been given a letter detailing the aims and purposes of my research (see Appendix 16, p.181).

The three schools were

‘Uplands’ - a mainstream mixed-sex comprehensive school

‘Oakwoods’ - a mainstream mixed-sex comprehensive school

‘Lakeside’ - a specialist school for children with physical and sensory difficulties

Uplands action research group (ARG) consisted of a

- Special Educational Needs Co-ordinator (SENCo),
- Assistant SENCo,
- Parent of a physically disabled young person who was a participant in stage one (Rocco)
- Parent Support Adviser (PSA)
- Parent of a young person with additional needs
- TA



Oakwoods ARG consisted of a

- Deputy Principal
- Assistant Headteacher
- Deputy SENCo
- Parent of a physically disabled young person
- Parent of a young person with additional needs
- TA

Lakeside ARG consisted of

- Deputy Headteacher
- Residential Care manager
- TA and Meal time assistant
- TA and inclusion co-ordinator
- TA and Nursery assistant

## **Procedures and measures**

### **Session One**

Discussion of vignettes from the first stage of my research (see Appendices 2-6, p. 149-153).

The content of these discussions and subsequent discussions in the group were recorded on a digital recorder, transcribed and analysed qualitatively using a content analysis (Crotty, 1998; Smith, 2008).

Participants were asked to talk to a disabled young person known to them about one of the issues highlighted in the vignettes. They wrote field notes and discussed this in the following session. O'Hanlon (2003) recognised that participants engaged in a process that involves them in interactive data collection brings about change in the dynamics of the relationships between all the participant researchers and, therefore, the group process forms part of the data and findings.

### **Session Two**

The participants discussed what the young people had told them and similarities and differences between these and the original participants were recognised. Participants were asked to discuss five key points they believed were important for successful social inclusion with a young person and bring this data to the next session.

### Session Three

Concept maps were drawn up in small groups outlining the five key points participants believed were important for successful social inclusion. These were later converted into a table for ease of comparison and to highlight emergent and recurring themes. Themes were ideas or categories that were given importance by the participants themselves.

The data was thematically analysed and conceptualised to form the development of new models which were recognised as useful for stimulating further debate and discussion in the domain of social inclusion. This formed part of the ongoing process of the development of understanding through the Plan → Listen → Discuss → Reflect → Change cycle of action research.

Evaluative comments were gathered and analysed qualitatively to explore how effective the ARGs had been in developing understanding, engaging participants in the reflective process and any intention to change practice (see Appendix 9, p.158).

Thompson (2007) asserted

*'where you end up and what you end up with (outcome) is inextricably connected with what you are trying to achieve (purpose), and the avenues you use to try to get there (process)...Purpose, process and outcome are inseparable'. (p.10)*

He contended that whether change is seen as 'improvement or as transformative' depends on whether change is seen as desirable or essential. The importance of respecting children's rights, hearing their voices and having their sense of belonging and friendships valued in their school communities I would argue is both essential and transformative.

This methodology acknowledges that within the transformative process of engaging in action research all participants are personally involved and develop their understanding and knowledge in collaboration with others. In terms of the validity and authenticity of action research it is essential that researchers are aware of their values and personal interests. This was discussed collaboratively in all three action groups in the first session where we talked about our own experiences as teachers, parents, TAs and other allied professionals working with disabled young people. Reflection and personal awareness was an integral part of the research process at every stage (Schön, 1983).

## Ethics

All participants were fully briefed by letter about my aims and purposes for this research and then further explanations and clarifications were offered verbally at the beginning of the first action research session. Written informed consent was gained from all participants and also the assurance that data could be withdrawn at any time and all participants and schools would be anonymised (see Appendices 15 and 16, p.178-181).

In order to ensure anonymity it is necessary to simply refer to this research taking place in an authority in the Southwest of England due to the particular identifiability of participants and settings.

The method chosen was congruent with my ethical stance as a social constructionist researcher acknowledging that the views of the disabled young people and education professionals, para-professionals and parent participants are constructed from their individual experiences and are all equally valuable and valid. My awareness of the subjective nature of my own viewpoint and personal perspective as a participant in the action research process is acknowledged. I recognise my influence on the process and my contribution as a Trainee Educational Psychologist, as a person who grew up in a family with a disabled father and as a parent of two sons.

# Results

## Action research findings

### Session One

#### Vignette discussions

The vignettes used in the action research groups were short, illuminative sections taken verbatim from the transcripts of some of the semi-structured interviews.

Discussion comments and field notes written by participants based on the vignette 'A room of our own' by Lara (see Appendix 2, p. 149) included:

#### Uplands:

*I feel and hope that our provision is more like the positive scenario described in that all friends are welcome.....children get together for warmth and a nice space not 'cos they need to or are made to. Some disabled young people choose not to use the support room and they are free to do so. (Assistant SENCo)*

The theme of choice is emergent here and these assumptions are later questioned after a discussion with a student at the school. Warmth is also emergent and both these themes are developed in the discussion.

#### Oakwoods:

*This is challenging. It's interesting isn't it getting that balance between meeting their needs and also supporting their personal*

*development. Do they all want that or might some want to have a space with more adults? Our students have access to different rooms, their tutor room or student support. (Deputy Principal)*

**Lakeside:**

*It's clear this young person wants a choice of where to go at breaktimes. (TA)*

*Choice is a difficult concept. Young disabled people in a special school setting are often structured to the point where they are unable to make any choices without prompting and permission. (Deputy Head)*

The structure or micro-management of the specialist setting pupils is later recognised as a barrier to children having the time or opportunity to choose.

Discussion comments by participants based on reactions to the vignette '**wheelchair tennis and friendship**' by **Chris** (see Appendix 6, p.153). include

**Uplands:**

*In a special school... and the children go in a taxi at the end of the day, they go back to where they're living. They don't know the child next door...So the social inclusion, it doesn't happen as well. (SENCo)*

*It's lovely to hear from the children's point of view as well, through the vignettes and comments from other students...there's a lot I don't know about it. Because we're not living that life!" (TA)*

Even at this early stage the participants are beginning to recognise that there is a great deal that adults don't know about children's experiences and views.

**Oakwoods:**

*He says he's more confident now and the sport has helped him make friends. (Deputy SENCo)*

*I wouldn't have thought of that part of the sport....that it would help them build friends....just the sport part I think (TA)*

**Lakeside:**

*At school most would seem to regard their classmates or transport pals as friends but have no particular friend (TA)*

*Forming friendships can be particularly hard on a practical note as so much of their day is organised by adults. Even a 20 minute break time most of that is taken up with toileting and snacks ...(TA and inclusion co-ordinator)*



*I think friendships- what we call friendships- are very rare here. For numerous reasons, time, opportunity. (TA)*

At this first session some of the adults in Lakeside don't think the children have 'friendships' but are becoming aware that 'time' may be a contributory factor. By the final session members have a more nuanced view and are more aware of how their students do value friendship but lack time and space for this to develop easily.

At the end of the first ARG participants were asked to talk to or interview a disabled young person about one of the issues on the vignettes and this gave some unexpected information to several of the participants about the reality of the school day for disabled students.

## Session Two

The second ARG, three weeks later, involved discussing the key points from our insights based on the young persons' vignettes and their conversations with disabled young people at home and school.

### ***Emergent themes from discussions***

Differences between parents....

- Some enjoy 'special' opportunities
- Some choose not to access what they considered 'unfair' privileges.
- Treating him the same and wanted....freedom and punishment.....amused by SENCo at Uplands saying she was proud of Rocco when he gets into trouble ("You must be proud a lot then!!")
- Contrasting with expressing worry and embarrassment when son gets into trouble at Oakwood ("*every time the phone goes....what's he done now?*")
- Protection and e-safety....don't do as I do, do as I tell you! (Byron, 2008)
- Being cool, being trendy, seen as important 'to fit in'
- Wearing uniform seen as important 'to fit in'

#### Differences between TAs

- *All* students like the student support base.
- Students like a *choice* of places to go.
- Room choice assumptions not found to be reality of practice in school

#### Differences between senior management and TAs and parents

- Some senior management missed the second session due to urgent matters within school
- Parents didn't miss any sessions

- Only one TA missed a session due to unforeseen circumstances

For further examples of discussions from session two see Appendix 13, p.167.

The group process was an important aspect of session two as well as the inclusion content. This is when the group started to bond through humour, common experience and purpose and a rapport began to build. This was important and helped sustain a positive atmosphere when discussions became more personal or views dissimilar. I was aware of needing to keep the space safe for more vulnerable members. At the end of session two all participants were asked to think of five key points that they thought supported successful social inclusion and to discuss these with young people ready for the final session.

## Session three

### **Concept maps**

Each school group divided into smaller groups of two or three people and drew a concept map (mind map) based on their collaborative ideas. In the table below I have organised the points drawn into five headings to show

emergent and recurrent themes but I have kept the key points and phrases used by the sub-groups themselves to also show differences in ideas, priorities and language used.

**This table shows the key points chosen by participants grouped as**

- Understanding and quality relationships
- Attitudes and friendship
- Access and support
- Choices (time and space)
- Equality and diversity

See Table 7. On next page for Key themes that emerged.

Table 7. Drawn from conceptual maps of five key points for developing social inclusion by action research groups

Lakeside	Key Point 1	Key Point 2	Key Point 3	Key Point 4	Key Point 5
	<b>Understanding and quality relationships</b>	<b>Attitudes and friendship</b>	<b>Access and support</b>	<b>Choices</b> <b>Time and space</b>	<b>Equality and diversity</b>
Deputy Headteacher /former outreach teacher	<b>Understanding and Co-operation</b> *Between parents, carers and staff *Differentiation, time and pace *A will to make it work *People to talk and work <u>with</u> each other	<b>Enthusiasm</b> *strengthens diversity *Then it will happen	<b>Support</b> *Physical, emotional, financial, practical, appropriate independence	<b>Practical solutions</b> *nothing is insurmountable	<b>Complexity</b> *all children are important *understanding other pressures
TAs and parents	<b>Good communication</b> *Free *Trusting *Safety	<b>Space</b> *A physical room to be with friends	<b>Access</b> *All areas of the community	<b>Time</b> *Staff members to co-ordinate *Young people time to access activities and socialise with friends	<b>Equality</b> *All members to be treated equally *Opportunity to do all activities

<b>Lakeside continued</b>	<b>Key Point 1</b> <b>Understanding and quality relationships</b>	<b>Key Point 2</b> <b>Attitudes and friendship</b>	<b>Key Point 3</b> <b>Access and support</b>	<b>Key Point 4</b> <b>Choices</b> <b>Time and space</b>	<b>Key Point 5</b> <b>Equality and diversity</b>
TA and Inclusion co-ordinator	<b>Collaborative creative work</b> *Arts projects *Bringing the community in and spending time together	<b>Opportunity</b> *Break times a joint space and time to socialise	<b>Access</b> *Funding issues *Out and about in the community	<b>Time</b> *Especially lunchtimes to socialise	<b>Education and information</b> *Improved training for TAs *Information for mainstream pupils. They may have pre-conceived ideas or judge on appearances
<b>Uplands</b>	<b>Key Point 1</b> <b>Understanding and quality relationships</b>	<b>Key Point 2</b> <b>Attitudes and friendship</b>	<b>Key Point 3</b> <b>Access and support</b>	<b>Key Point 4</b> <b>Choices</b> <b>Time and space</b>	<b>Key Point 5</b> <b>Equality and diversity</b>
Assistant SENCo and TA/parent	<b>Feelings</b> *Relaxed, included, comforted, supported, safe, happy	<b>Friends</b> *Common ground, *Games	<b>Structure and support</b> *Time and knowing when to back off	<b>Own place</b> *Safe place of own choice *Own place/room	<b>Choice</b> *Freedom, control/ *Boundaries

Uplands continued	Key Point 1 Understanding and quality relationships	Key Point 2 Attitudes and friendship	Key Point 3 Access and support	Key Point 4 Choices Time and space	Key Point 5 Equality and diversity
Parent Support Adviser (PSA) and TA/parent	<b>Differentiation</b> *Work from teachers to cater for all learning styles *Understanding of support elements needed to deal with individual needs	<b>TAs</b> *Good match of TA /students getting the balance right	<b>Support</b> *Good level of time and investment in support structures eg. TAs, learning mentors, behaviour support, PSAs	<b>Room</b> *A room they can go to <u>if</u> they want	<b>Equality</b> *Not being treated any different than anyone else in the wider community
Parent / Trainee Educational Psychologist (author)	<b>Feelings</b> *Special people to confide in, intimacy, sometimes jealousy, friends and TAs *Feeling close and belonging	<b>Friends</b> *Lots of friends *Going out *choice to select and decide *no pressure *feeling included	<b>Access</b> *Increased access at times, all areas accessible *Access to own TA for security and privacy regarding physical difficulties	<b>A place to go</b> *Choice of a room or a year area or outside space according to where friends are	<b>Equality</b> *Seen as like everyone else except when they choose *Able to benefit from differences when possible, increase social capital

Oakwoods	Key Point 1 Understanding and quality relationships	Key Point 2 Attitudes and friendship	Key Point 3 Access and support	Key Point 4 Choices Time and space	Key Point 5 Equality and diversity
Deputy SENCo and TA	<b>Understanding adults</b> *Adults to relate to and talk through issues	<b>Peer support</b> *Friendships	<b>Structure and support</b> *Access *Clubs *Learning mentors *Support from outside agencies	<b>Included in everything</b> *Sports days *Stop the clock days *School productions *Aspirations week	<b>Choice</b> *Safe zones *Tutor groups *Friends
Parents and Assistant Headteacher	<b>Understanding adults</b> *Teacher organising inclusive activities for whole form	<b>Peer support</b> *Identifying children that have experience or empathy with disabled young people  *Encouraging inclusive groups that are more socially accepting	<b>School support</b> *Clubs *Activities *School uniform	<b>Encouragement</b> *To take part in everything	<b>Information</b> *Clubs *Assemblies *Newsletters

**Thematic Analysis shows these themes recurring**

- **Quality relationships** – communication, trust, teachers and TAs leading/modelling inclusive practice, sensitive, understanding of



individual needs, feelings, friendship, friends, identifying empathic peer groups,

- **Access and support**- Access, support structures, clubs and activities in school and wider community, outside agencies
- **Choice** - time, room, choice of space, participation, opportunity, feelings
- **Equality and diversity** –complexity, opportunity, individuals, difference and commonality acknowledged, information and education

The theme of friendship is particularly recurring, which is not unexpected, but the different elements of friendship that occur is illuminative, for example, use of empathic and socially accepting peers to form inclusive or friendship groups and the recurrence of an understanding of choice as a key issue. These themes will be explored further in the discussion section.

Despite not being implicitly stated the theme of listening to young people's views is implied in each section for example, '*Adults to relate to and talk through issues*' and '*people to talk and work with each other*'

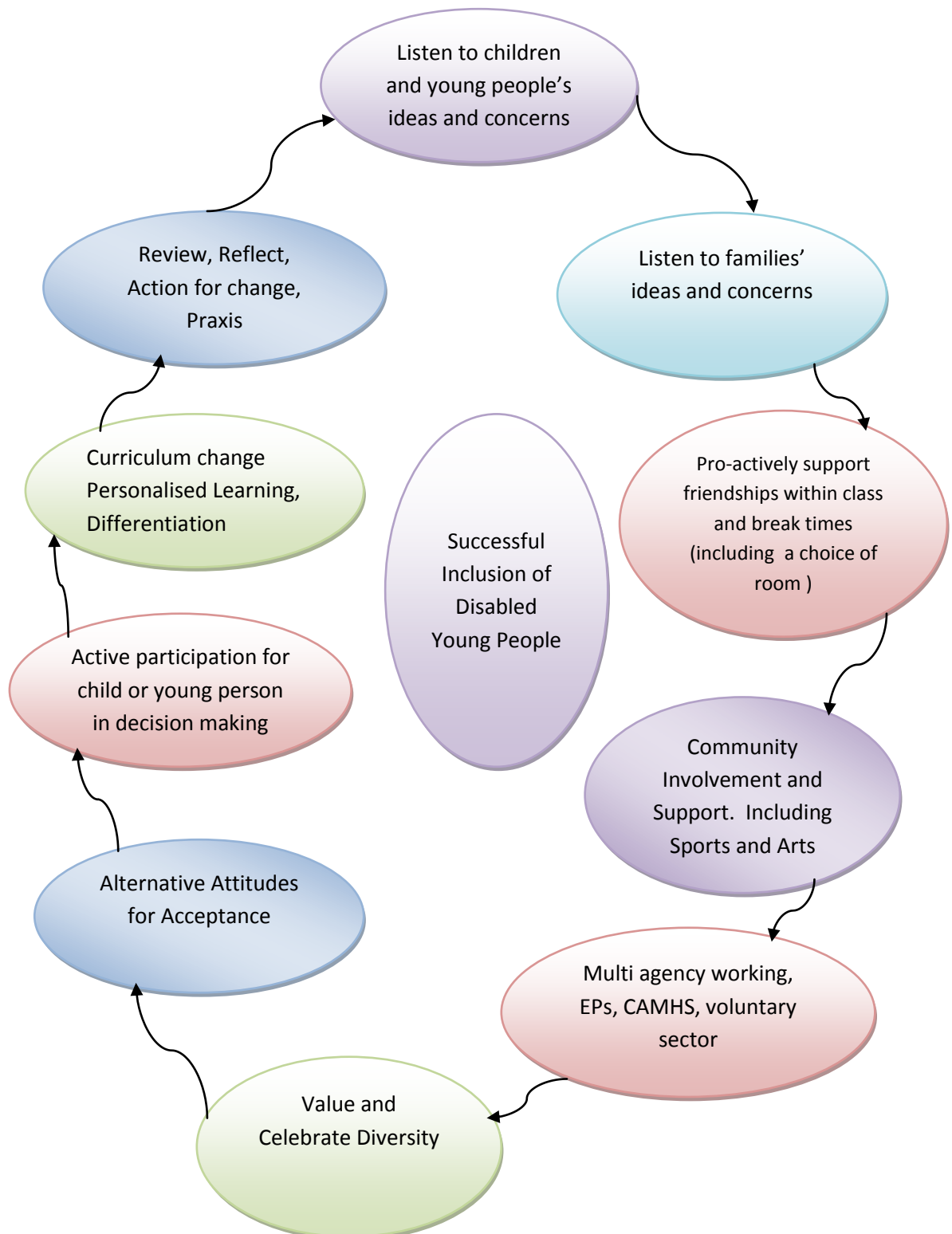
In this session we looked at all the concept maps that had been made in the group and compared key points.

### **Social Inclusion model**

I then shared with the group the framework I had developed from my initial research (see Figure 2, p. 52) and asked for comments and critique.

Comments were generally positive but it was noticed at the Lakeside that I hadn't included multi-agency support and that was felt to be important. I have now added this to my model see Figure 3.

Figure 3. Social inclusion model 2 (social inclusion model 1 revised)



We also discussed a simpler conceptual model that I had developed from the key themes that had emerged from my research to date.

Figure 4. Conceptual social inclusion model



Feedback on this model included that it appeared that everything developed from friendship whereas some people felt that the model worked better the other way round that the conditions for friendship and quality relationships to take place were often dependent on the other concepts like access and choice being addressed first. The key concepts were acknowledged, however, as being authentically recurring themes of our action research

A further development and reconceptualising of this model is contained in the conclusion.

### **Evaluation comments**

The evaluative comments suggested that talking to young people, thinking, understanding and reflection have taken place, and include...

#### **Parents**

*'Before I always thought I knew what my son wanted and needed but now I have listened to what he feels and wants and have understood a lot more.'*

*'I found it useful to hear views from other parents, teachers, members of school staff. It also encouraged me to discuss topics discussed with my son.'*

*'these sessions made me stop and think about where my son is and has led to more in-depth discussion with him about how he sees himself within the school environment. Something I don't think I would have done otherwise.'*

#### **TAs**

*I thought I had more understanding of general needs of the young disabled I knew. ...I was surprised to realise my understanding was less than I thought. ...I think it would be a useful place to start with changing things.'*

*I have learnt not to presume I know but to ask more. Not all young people are the same. We need to have discussions with pupils about their free time and find space they want to use.*

*...It has really made me think more about what we offer our students in terms of their free time and inclusion. We need to look at how we can offer the students their own space to socialise and give them some free time to do this.*

*...these sessions have really made me think about what the children think/feel. I think this has opened my eyes to the difficulties they may face with social relationships and friendships. I have found it particularly useful and interesting to share views with colleagues ...*

### **Senior management**

*We are due to review our inclusion policy and we would like to include parents in that process and what we have been discussing in these action research groups.*

*I am finding out more about the emotional needs of our pupils and have realised how much there is to learn.*

*Questions to make me think!*

## **SENCOs**

*...We have changed our practice as a department and it has made us more aware of seeking to make as much as possible a 'normal' teenage environment....*

*I feel more confident about how disabled young people feel about a variety of social inclusion issues since specifically taking time to discuss options with them.'*

*The importance of talking to students has been highlighted. Having time dedicated to thinking about these issues has been very worthwhile.*

## **Parent Support Adviser**

*it's been good reflective practice experience to see others perceptions of the school and its practices and facilities offered to all students.*

## Discussion

The level of engagement, humour, reflection and willingness to critique own practice demonstrated the action research process had allowed the groups to develop trust and cohesion. Importantly the findings also suggested the research had been highly valued and that a recognition of how we could support disabled young people to further develop their friendships had been achieved. This required a high level of honest reflection and a heightened awareness of the barriers we as adults had placed in the way of children developing those meaningful friendships. Barriers such as choice, time and space re-occurred not only from the sharing of the vignettes but from participants own discussions with students and the consequent action research process.

### **Listening to the views of disabled young people**

Exploring the vignettes allowed the attitudes and beliefs of the action research participants to be shared. This process enabled people to compare and examine their knowledge and values in a supportive but challenging way that allowed for deeper understandings to emerge. Specific findings from the first session included participants questioning whether students *really* felt that they had a choice of where to go at break times. Additionally whether students had *time* to socialise with friends at break times at all at Lakeside and that a private space away from the classroom occupied by teachers and TAs was not considered in the recent

new build (Oliver, 1996; Swain et al., 2003). It was illuminating to the staff to recognise that some pupils walked up and down the corridors at break times to have '*private chats*' and '*laughs*' with their friends. This led some staff to question their earlier stated assumption that pupils at the school did '*not have true friendships*' as '*we understand them*'. Lewis and Lindsay's (2000) research, and my initial findings that children do not lack competence for friendship but often opportunity, were supported by the new insights developed. This respectful challenging of assumptions was a feature between members of the groups and allowed recognition of the validity and usefulness of the social model and disability rights to emerge. For example, that non-disabled adult assumptions provided barriers to children's friendship and inclusion rather than the level of physical impairment (Oliver, 1996; Rogers, 2007; Swain et al., 2003).

The aim of encouraging action research participants to talk with disabled young people themselves was viewed as problematic by teachers at Oakwoods but not by others in that group. This was illuminating as it showed sensitivity to children's aversion to being '*shown up*' (Lynas, 1986). A deeper understanding of related research and our experiences as researchers however, clarified that young people did want to be talked to, listened to, and *asked* what they wanted in quite specific ways (Asprey & Nash, 2005; Thomas & Vaughan, 2007). This debate led to a meaningful discussion about '*difference*' and '*fitting in*' and a heightened awareness of the need for an individual knowledge of the students. Sensitivity on the



part of professional adults to judge what is valuing views and opinions and what might be construed as intrusive or '*spotlighting difference*' was agreed (Norwich, 2008; Rogers, 2007). In recognising the authenticity of the teacher's experience and views and being able to respectfully offer alternative viewpoints a consensus was reached that an informal approach was more appropriate for certain children. The quieter ones, the teachers suggested, who may experience further vulnerability and marginalisation, should also be heard so that they have an equal opportunity to become active participants (Billington & Pomerantz, 2004).

This highlighted a potential weakness of my initial research in that the ease of eliciting the views of certain participants could have resulted in less attention and time being spent with participants who were more difficult to understand. My desire to counteract the experience expressed by Jackie, who has cerebral palsy and speaks slowly with reduced clarity, that adults often did not take time to listen led me to spend as much time as possible with her, keeping sessions short and returning several times to complete interviews. I felt I was less successful in gaining the views of James, however, who had no verbal communication and this is something I would choose to address in future research (Clarke & Venables, 2004).

### **Reflecting on new information**

Participants in the action research groups remained actively engaged in the process of the research and came to the second session with new insights

gained from discussions with disabled young people (Alderson, 1993; Clarke & Venables, 2004; O'Hanlon, 2003).

Lara's vignette inspired Uplands to create a room as she described where TAs were only rarely present and young people were trusted and empowered to be competent to manage who used the room, noise levels and appropriate behaviour. Reflections revealed the success of Lara's room 57 may be that despite the general lack of facilities it had a small area with a partition and although conversations can be overheard students are able to gain a greater sense of privacy on occasions where this is preferred to being in a crowd. This was found particularly pertinent for physically disabled young people who could not easily find a quiet space in between the lockers or in the cloakroom to have a private conversation with friends and thus experienced an inability to be invisible when they chose.

Also in talking further to disabled students participants learnt that tutor rooms allocated were inaccessible at breaktimes and lunchtimes and that the assumption that access to a room of choice with friends was unfounded. This was a particularly strong example of praxis occurring due to the action research process where direct information from students led to reflection and practice change by professionals (Schön, 1983; Freire, 1972; O'Hanlon, 2003).

Language from my initial research such as *'stuck like glue'*, *'breathing down my neck'*, *'in between me and my friends'* emphasised that TAs and carers required absolute sensitivity to avoid becoming socially disabling for young people whilst attempting to meet their physical and academic needs. The strength of the action research methodology rather than delivering pre-designed INSET training was that these understandings could be discovered and reflected upon in a collaborative and respectful atmosphere of mutual learning. This led to more open and honest recognition of weaknesses in current practice and changes that could be made than an 'expert' INSET delivery may have achieved. This speaks strongly to practice for EPs. Traditional INSET has a place but the strength of collaborative action research has stronger echoes of the Consultative model (Wagner, 1995) that many services promote. The issue of time for the EP, parents and the school is important but research suggests that in order for INSET to be effective it also requires input over time rather than one off presentations. Ideally an action research project could be developed across a whole year and the development of school and EP relationship and research would be strengthened by opportunities to plan, do, reflect and change (Freire, 1972; O'Hanlon, 2003, Schön 1983).

### **Conceptual maps**

The conceptual maps drawn by the participants were useful in clarifying thinking and exploring similarities and differences in key points that participants felt enhanced social inclusion. It was clear that participants were drawing from insights gained from the vignettes, their own

discussions with students and the in-depth discussions that had taken place during sessions one and two as well as their unique insights as parents and professionals.

### **Quality relationships**

The recurrence of quality relationships between peers and adults highlighted the sense of being valued and understood. Fullan's (2003) complex change lessons recognise quality relationships as part of the mobilisation of '*social attractors*'. The centrality of quality relationships is fundamental to the successful work of the EP whose professional interpersonal and communication skills aid the development of genuine rapport and relationships of trust with children and families. Friendships and feelings are also central to a child's emotional well-being Gilligan (2000) recognised and this view is supported by both stages of my research. He emphasised the importance of spare time, breaks, off-task times to maintain friendships and build resilience. A discussion around this subject in session three in Oaklands helped all the adults present recognise how much attention we pay to keeping children on-task and how little attention is paid to their social need to be off-task on occasions. The nursery TA in Lakeside also suggested that disabled young people may have missed out on play opportunities ensconced in playhouses, under tables or in dens as young children. This may be a further reason why it was particularly important for disabled young people to not always have to remain 'visible'.

The active ways many of the young people sought out friends and a place to talk confirmed the high value placed on friendship by disabled young people. This included Chris's acknowledgement that his 'self-esteem' was raised by his friends who sustained him when he disliked the lesson or challenged him through wheelchair tennis. Also Michael and Rose who walked the corridors to find a space to talk and laugh and Rocco whose mother revealed he will catch a sequence of buses in all weathers, despite his physical difficulties, to meet up with his friends.

The importance of the quality relationships that parents, teachers and TAs provide was also highlighted in the emergent themes. The importance of having a close relationship that gives a great deal of security and warmth but not emotional dependence for TA or student was discussed and an agreement reached that the issue of social inclusion is complex (Norwich, 2008). For example, Jackie felt 'annoyed' and 'frustrated' by the amount of attention she received from her TAs and carers, others reported it is 'just right'. Jo emphasised that it was helpful to have different TAs who are subject specialists rather than always the same person. Rocco can feel jealous if 'his' TA is giving attention to other students. The SENCos talked sensitively about their awareness of these issues and balancing the needs of students, staff and timetable complications. However greater insight into the practical consequences of where a TA positions a child in a wheelchair or where they position themselves in relation to a child and their friends was valued from discussions of the in-depth semi-structured

interview data and parents voice about how children described their day and led to the change of practice described at the end of the discussion.

### **Practical solutions**

Access to clubs and activities and the wider community was seen as a pressing issue for Lakeside. Despite their efforts to encourage after school activities transport issues made these generally unsustainable. Useful debates about how to ensure wider access for children into mainstream playgrounds and how to develop community and joint arts projects further were fruitful. The role of voluntary agencies in the local authority that ran initiatives to widen participation amongst marginalised or vulnerable groups of children was discussed and the value of joint-agency working that was more able to support the child in the wider system of the home and community was acknowledged.

### **Choice**

This theme was strongly evidenced. Social inclusion and friendship was highly valued by all the original participants and quickly became an area where schools and parents recognised they experienced internal conflicts between choice and protection, both physical and online e-safety. The complexity of online e-safety and the need to educate the young people themselves as advocated by Byron (2008) was a concept that was developed in the discussion groups. Parents acknowledged that their own learning and awareness of issues of choice and e-safety needed to constantly re-assessed to enable their children to develop their own e-

safety skills. This was an area where the participants choice and control (levels of supervision) was mediated by an awareness that they needed to give good safety information to their children and trust them to recognise potential dangers themselves (Byron, 2008).

Also wider choices for their children's education had required 'a fight' in terms of access to resources and information and, therefore, inclusion often remained a dilemma for young people, parents and professionals (Norwich, 2008). An evidence-informed approach, therefore, that supported the EP to working collaboratively with parents and schools towards inclusion in times of stress and vulnerability was valued. My research has suggested that the disabled young person would like a true voice not a 'tokenistic' voice (Hart, 1992). The EP, therefore, as practitioner and researcher, has a unique role in effectively supporting children and families to access inclusive education or ensuring community inclusion if a child is placed at a special school.

### **Equality and diversity**

Oliver's (1996) 'new ideas' for inclusion remained salient. Celebrating difference required a school ethos where teachers recognised a child's right to differentiation and having their needs met rather than requiring the student to endlessly fit into an unsupportive environment. The concept

that inclusion is a process that must be fought for recognised the reality of many families experiences as highlighted by the parents at Uplands.

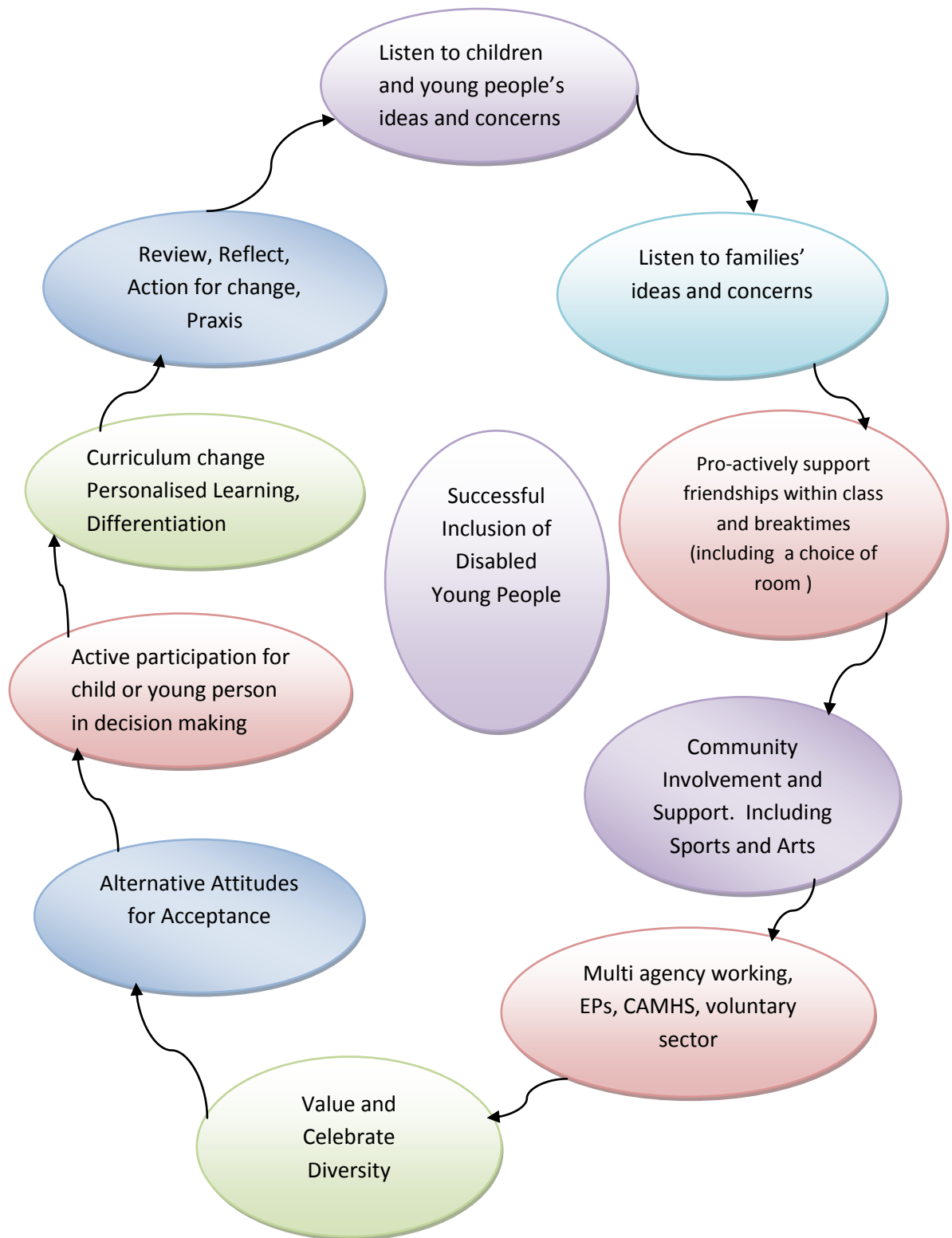
The value of the social model of disability was helpful but Norwich (2008) contends that a biopsychosocial model that contains a meta-perspective of a synthesis of theory, epistemology and research paradigms is more useful in real world situations. Nevertheless a depth of understanding of the political and social construction of disability that researchers offered (Mason, 2005; Oliver, 1996; O'Hanlon 2003; Rogers, 2007) was valuable in navigating the complexities of the system.

### **Evaluation and reflection on the process of the action research**

The evaluation of the model I had developed from the first stage of my research (see Figure 2.) showed expected similarities to the group conceptual maps. Lakeside's recognition of the value of explicitly adding the multi-agency element was helpful and stimulated productive discussion of future joint-working and research possibilities. Model 2 (see Figure 3.) is offered not as a definitive solution but as an ongoing process of evidence-informed conceptualising of successful social inclusion. Thus the views and contributions of disabled young people, their families and schools to the research process are respected and promoted. I suggest that models are useful stimuli for individual schools and communities but that examination, critique and change to suit particular needs, identities and unique situations are appropriate.



Figure 3. Social inclusion model 2 (Social inclusion model 1 revised)



## Evaluation and Change

Participants wrote evaluative comments at the end of the final sessions which are included in the results section.

Recurring themes in the comments included that the action research had been useful in thinking about issues. These had stimulated more in-depth discussions at home and that listening to their own students had challenged some previous assumptions. The research process allowed quality time to discuss important issues of inclusion with colleagues and to gain insight into the views of students and parents.

Fullan (2003) suggested that change is not an event that occurs in such a way that a 'before' and 'after' could be recognised and measured. He defined change as a process and, therefore, the fluid and ongoing change process of this action research project is acknowledged.

However, O'Hanlon (2003) proposed that action research goes beyond the reflective practitioner model of research created by Schön (1983) by expecting active change to 'realise intentions'.

In terms of bringing about change through action research intentions included

- Developing regular parent discussion groups
- A change to length of lunch break in the specialist setting

to allow time for socialising and friendship development

- Including parents in an Inclusion Policy review
- Asking disabled young people what rooms they would like to have available at break
- Ensuring all rooms allocated are accessible
- Including pupils on interview panels for TAs
- Asking pupils where they want to sit at lunchtime
- Making sure TAs are not sat in between pupils and their friends during lesson or break times unless invited to be
- A joint arts project with a mainstream school

An important aspect of the change intentions that the schools had made is that these stemmed from parents and schools active participation in the action research process. Therefore the ownership of these changes belonged to the research community and are more likely to be sustained by the quality of their purpose (Fullan, 2003). Although the groups are now not meeting formally the continuing development of the quality relationships between the members, and the planned greater inclusion of parents, will enable those who are motivated to make changes to promote social inclusion in a more supportive environment (Georgiades & Phillimore, 1975).

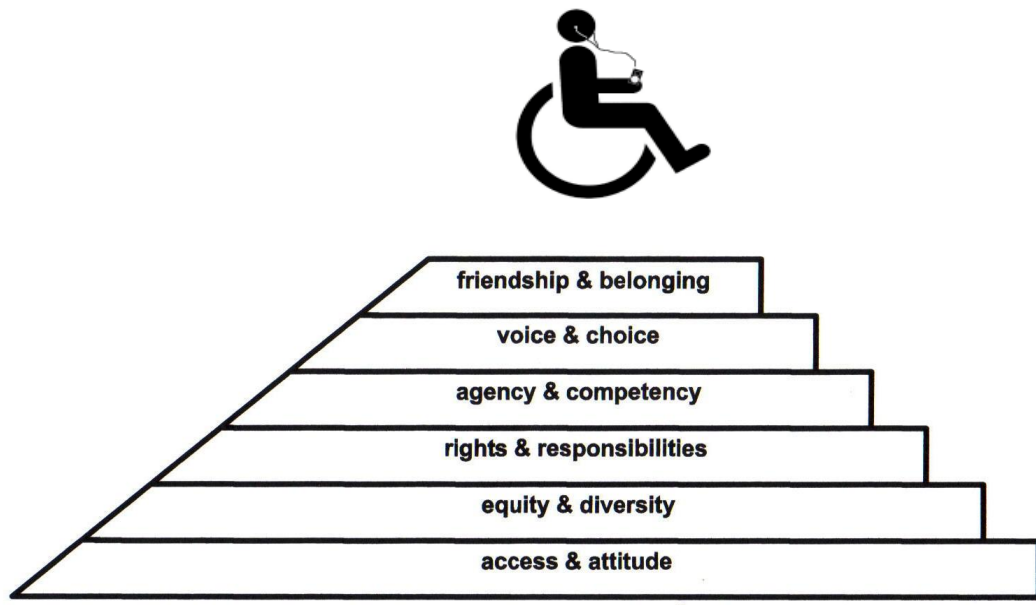
## Conclusion

The links between the action research model and the role of the EP in schools is worth highlighting in this study. Namely, that in order to achieve systemic change in schools the EP need not be a hero-innovator but more usefully an ally who through supporting, valuing and promoting pupils' and schools' own competencies can be a catalyst for change. Crucially, Dilts et al. (1990) suggested that a 'small change in beliefs can be much more effective than a large change in behaviour' and, therefore, empowering communities to believe in their own agency for change is the most significant outcome that this action research project has achieved.

O'Hanlon (2003) emphasised that equality and justice are sustained by the quality of our respectful personal relationships with the communities we support. In attending to young peoples' friendships, sense of belonging and, therefore, social inclusion it is more likely that inclusive schooling will work. Rieser (2000) believed that society experiences a reduction in prejudice and discrimination against disabled people as difference becomes part of everyday experience in schools and the wider community. The act of friendship leading to real social inclusion, therefore, not only transforms the disabled young person's experience of education but contributes to a society where everyone belongs and is valued for their contribution.

A final model based on the learning from the process and content of these action research groups and offered as a basis for stimulus for further research is shown below.

Figure 5.



**Six steps to social inclusion? - Discuss**

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## Appendix 1

### Example of a transcript

Jackie      1st interview      Transcriber CH

*Claire*      *I've got two sets of questions, some of them are questions that I thought would be good to ask and then some of them are questions that when I spoke to you and I spoke to other young people in schools, they said well these are the sorts of questions you should ask.*

Jackie      Ok

*Claire*      *Some of the questions are a bit long but what they're supposed to be is questions that aren't a right or wrong answer or a yes or no answer*

Jackie      Right

*Claire*      *So whatever you want to say is absolutely fine there's no right answers. Ok? Are you ready for the first question?*

Jackie      Yea

*Claire*      *What opportunities do you have to make positive relationships with other young people in your school?*

Jackie      I don't really, but, well I have the middle of the atrium where I just sort of sit on like in the middle and other people sit on, and people from my year sit on one side, but apart from that I don't really.

*Claire*      *So where do you sit when you're in the Atrium?*

Jackie      In the, slap bang in the middle

*Claire*      *In the middle, is that where you want to sit or is that where the TAs put you?*

Jackie      That's where the TAs put us

*Claire*      *Right*

Jackie      'Cos it's convenient for them. It's not where anyone would want to sit, it's just where they like decide.

*Claire*      *So they decide and do they put you with a group of people that they know are your friends? Or do they put you with*

Jackie      They put us with other disabled people



- Claire* How about actually in lessons, do you think you get many chances to make friends in lessons?
- Jackie Well in lessons I sit next to a couple of people who I get on with but most of my class is, we're mainly in seating plans and I'm mainly away from those people that are my friends. Which is slightly annoying but
- Claire* So the teachers have decided on a seating plan where you should sit in the class
- Jackie Yah
- Claire* And that's far away from your friends?
- Jackie Yea
- Claire* So you don't get chance to go and think, 'ok well I'll sit near this group of people that I like'. Ok. Do you see your friends out of school that you've got in school? Or just in school?
- Jackie I see one girl who is a year older than me outside of school very occasionally, but apart from that I don't see anyone else.
- Claire* Ok, this is a question that I think you'll like because you helped me make this one up. In what ways do your TAs help you or make it tricky for you to develop your friendships?
- Jackie They, I can't write so they have to sit on my writing side and all my friends sit next to them, so I have to kind of talk over them to talk to my friends which I find a bit tricky.
- Claire* So they sort of sit on the right hand side and then your friends sit the other side so you're having to talk across them if you're talking to your friends
- Jackie Yes
- Claire* And do you find the TAs help you to make friends in any way?
- Jackie Not really, they just say, 'it's your job to make all these friends so just go out and do it' and I'm like, 'I can't, because you're always there' and they're like, 'yea, but' and I'm like 'ok'. Now I just shut up and get on with it really. Just leave them to do, make up stupid rules. I do shut up and go on about my day for about five hours and then go home again. Bit bad really, but oh.....
- Claire* Ok, what do you think the adults whether they're TAs or teachers in the school, could do differently to help you make friends or to help you keep friends?

Jackie They, if we're talking about keeping friends, they could like sit on the other side, on the table, they could like, instead of sitting right next to me, they could sit on the other side of the table, but they don't.

Claire *So they're not aware that they're always sitting in between you and your friends?*

Jackie No

Claire *Ok*

Jackie And when you tried to bring it up , they're always like, 'but you had the chance to talk to your friends' and I'm like, 'but I didn't then because you was sat there, so I can't really talk to them while you're sat there because I don't like talking to them, I don't like talking to my friends while they're there, because I talk about other stuff mainly about them, but I don't like it because I know they'll all hear and say it back to my supervisor who oversees my care.

Claire *Right*

Jackie And so I'm being myself? And then I'll get hauled up in front of the head teacher for being rude when I'm actually being a normal teenager. But yea, it's fun not.

Claire *Not fun, no. So you just don't get chance to chat with your friends like other people do*

Jackie Because they're always

Claire *Because the TAs are there and they're going to hear what you say and they might not like what you say.*

Jackie Yea

Claire *Even though it's just normal teenager stuff*

Jackie Yea

Claire *Yea, so that just makes you just be quiet and not try and talk to your friends in front of them, does it?*

Jackie Yea

Claire *Ok, so if they sat further away from you in lesson time or they just sat on the other side so that you could just talk directly to your friends, that would be better?*

Jackie Yea

*Claire*      *What about at break-times, when they put you in the middle of the Atrium, do the TAs then sort of go away and leave you to talk? Or are they around close?*

*Jackie*      The TAs have breaks but some of us need, well most of us are, need health care assistants, but just like fulltime care, which means that after the TAs go, the people who are holding your lunch are there, so you can't really have any kind of serious conversation and it's kind of in a weird way losing my friends, because they think, 'oh, her TA will just get involved anyway, so there's no point in talking to her'. And I'm like, 'but my TAs aren't speaking for me' but they're like, 'your TAs always talk anyway, so we won't talk to you for breaks and lunch'. I'm on my own really.

*Claire*      *And how do you feel about that?*

*Jackie*      I don't feel that great and that's why I'm always quite, I always like have this face on, because I'm annoyed

*Claire*      *Yea*

*Jackie*      But if I say to them 'I'm annoyed' they'll just like get really narky and say, 'well, you know what you can do' and I'm like, 'yea, I know what I can do, but you can still like stop doing it' Like you can always deny our help and we're like, yea we can't can we? Because you're like say you need to help us anyway so. So it's a bit annoying.

*Claire*      *So you're kind of stuck with them basically. Ok, thanks Jackie.*

*Jackie*      That's ok

*Claire*      *So how important are your friendships to you?*

*Jackie*      The ones I have and the ones I find it quite strenuous to keep are really quite important, because I have so little anyway, I only have like one that if I don't keep that one, I'll be alone again I suppose.

*Claire*      *And that's your friend who's in the year above you, is it, that you mentioned earlier, you're thinking of?*

*Jackie*      Yea. But my friend who's in the year above me, don't go to school any more, so I'm basically trapped with a load of boys in terror from flying everywhere, but yea, so it's basically me.

*Claire*      *Are the children in the atrium, in the middle with you*

*Jackie*      Yea

*Claire*      *Are there other children that use a wheelchair or have a physical disability? But they're not necessarily your friends, they're just*

Jackie No, they're just like piled together all of us, and we're told to, and in a way we're told to 'make friends with these people, they're the people you're being with for the past five years.' So in a way we end up like making friends anyway, but we all know that we're not each others' friends. It isn't like

*Claire So it's not about choosing the people that you might get on best with, it's about who they think that you*

Jackie It's about, you'll love these people, you have something in common with them so you've got to be friends with them for the past five years. I'm like, 'great!'

*Claire Ok*

Jackie It's a bit tedious

*Claire Do you think about friendships or worry about friendships at all?*

Jackie I don't worry, because I know if I do worry I'll just get more pain and it'll be a vicious circle, but in a way I'm kind of, I kind of don't think of it at the moment, it's really quite bad but

*Claire You don't think about it because you don't want to get upset?*

Jackie Yea

*Claire And if you get upset and stressed, then you get into more pain, do you?*

Jackie Yea

*Claire As you get tense?*

Jackie Yea, and my hip starts doing the fandango and then my back clicks and everything goes downhill, so I just don't tend to think about it.

*Claire Thanks so much Jackie. I think we should stop there cos you're looking tired and I can come back again next week if that's ok?*

## Appendix 2

### Examples of raw data

## Vignettes (taken directly from transcripts)

### A room of our own vignette

*Interviewer: How were your friendships at your last school?*

Lara: At the other school it was really different I had much less friends there. My TAs stuck to me like glue. They were control freaks and wouldn't let me hang out with my friends. They used to make me go to rm 10 and then 1 TA could look after all the kids with SEN but they wouldn't let my friends come in most of the time. They wanted me to stay in rm 10 cos they were over-protective but I wanted to be with my friends. It was very difficult. Here, rm 57 is way better, my friends can hang out with me.

*Interviewer: Can you tell me some more about rm 57?*

Lara: I can invite who I like to rm 57. We don't let it get too overcrowded, a sensible amount is allowed. If it gets too crowded then we can ask some to leave or Bridget will just come in and kick some out which is quite funny. She'll just check how many's there and what they're behaving like. Just general anyway. So there's no TA there all the time which gives us a lot of independence which is really, really good. Yeah we get a helluva lot of independence whereas as in rm 10 at my last school we were being monitored, we were being watched, we were being told what to do, our friends weren't allowed in, so basically they were controlling us.

### **Appendix 3 Social networking vignette**

*Interviewer: Is there anything that adults could do differently to help you make or keep your friends do you think?*

Rose: Well since we already are friends, well and we're still being kept friends and that, there is one way I would like to get in touch with them, if they had email addresses, email address, then I would email them and say, 'how are you doing?' and probably organise something with them, but asking our parents first, like that, and say 'would you like to do this? Would you like to go, you know'. Anyway like we could think of or going out to each other's house and have girly times. That was what I was thinking of doing.

*Interviewer: So can you email at the moment or are you not able to?*

Rose: I've got my own email address but I don't know theirs. I mean I would like permission to know their email address

*Interviewer: Yes, their email address, so how would you go about doing that do you think? Would you ask their parents or would you ask your teacher or your TA if they could organise that?*

Rose: Well, it needs to know if they've got an email address, but then probably ask permission if we could use it, you know, just like send emails, because my friends in my class already, I know their email address so I email them. So friends in my class I can email them

*Interviewer: Because you know them?*

Rose Yes, I know their email addresses because they're in the same class as me, but Jenny and Lucy I would like to know theirs, because they're not in my class and I don't know even if they've got an email address...And probably Jenny and Lucy might need permission from their parents as well, to see if they can give me the email address.

*Interviewer: So you could give them your email address, could you?*

Rose: Yes I can give them my email address

Interviewer: And then if their parents say it's alright, they could email you?

Rose: Yeah

*Interviewer: And then you'd have theirs?*

Rose: Yeah because then once I get their email, it'll show at the top who's it from and that would be their email.

## Appendix 4

### Accessibility Vignette

Interviewer: Since you've been at this school have you ever not been able to get into a lesson or have you always been able to access everything?

Chris: Yes I've always been able to access everything all the lessons. Once the lift broke down but school got onto it very quickly and it was repaired in half a school day. So we were all back to our lessons the day after.

Interviewer: Yes so they recognised how important it is that you have full access to every part of the school?

Josh: Yeah the caretaking departments they've made everything wheelchair friendly. Everything's accessible to get in, there's ramps. They've just installed push a button on the wall and doors automatically open. They installed that for us and they've put automatic doors in on the heavy doors to get into the entrances so that's made it a lot easier.

## Appendix 5

### Being included, participating vignette

Interviewer: Is there anything else you'd like to tell me about friends?

Chris: Elmside always included me. I'm happy and confident now. When I first joined I was down and didn't know that many people so it was a lonely place then but after the first day I met new people and it was fine again

Interviewer: So was it meeting people and making friends that built your confidence?

Chris: Yeah. Yeah. Absolutely built my confidence. It's got me where I am today

Interviewer: And did that happen through being in the class with them and being included?

Chris: yeah there's always one person that you can latch onto sort of thing when you get there then obviously you meet their friends and you get on well with them and you make new friends when you go on different trips and that. On the first day at St.Marks I went to the PD department straight away and I met all the TAs and they were really friendly. And I went to a French lesson and I made friends with a boy called Ben straight away.

Interviewer : Do you think that having a PD unit here at St.Marks makes a difference?

Josh: Yes because you've got a unit of people who are specialised to help you and we get to help in the interview process as well. Me and Jo interviewed a lot of people and we gave our opinions. And we see the TAs more as our friends. We call them by their first names and they call us by our first names. And my tutor, who's a teacher I can tell her things as well and talk to her.



## Appendix 6

### Wheelchair Tennis and Friendship Vignette

Interviewer: Are you happy at this school?

Chris: Yeah very happy at Elmside. Obviously I wasn't too happy with my last school and that was a down part of my school life and that but here's brilliant. I was really low on confidence at my last school anyway but Elmside has done so much for me. They're the ones that got me introduced to wheelchair tennis and they're the ones I've got to thank for getting there and meeting all my new friends. They've helped me a lot confidence wise.

Interviewer: Do you have a different set of friends out of school?

Chris: Yeah I meet up with my friends who go to this school but obviously because I do wheelchair tennis and that I've got a lot of friends who do wheelchair tennis so I meet up with them quite a lot and obviously I get on with their friends so...I meet up with my friends in school sometimes as well. Out of school we all merge. All my friends out of school know the people I do tennis with. So we all know each other. It's like a circle of friends and then we all meet up and that in town or something.

Interviewer: If you didn't do the wheelchair tennis or any of the sporting activities you do how do you think that would alter, if at all, your feelings of having friendships outside of school?

Chris: I don't think it would make too much of a difference but when I started doing wheelchair sport, and it's only started a couple of years ago and it opened up, I met so many new people, and it was a really good time. I met a lot of new people going up country and that. So I made a lot more friends. So it would be a bit different but I've still got good friends in school and that.

Interviewer: So when you're not doing your sport out of school what sort of things do you do?

Chris: I go into town usually with my friends. Play on the games consoles and that but most of my friends have got games consoles so we can sit and chat to each other. So communication and that and obviously we type on MSM to each other.

## Appendix 7

### Semi-structured Interview Questions

#### Researcher's Questions

- 1) What opportunities do you have to make positive relationships with other young people in your school?
  - a) Do you see your friends out of school as well or just in school?
  - b) In what ways do your TAs help you, or prevent you, from developing your friendships?
  - c) What could adults do differently to help you make or keep your friends?
  
- 2) How important are friendships to you?
  - a) Is this something you think about or worry about?
  - b) Do you feel like part of a group of friends in school?
  - c) Do you feel like part of a group of friends out of school?
  
- 3) Do you think you would have more or less friends in a different school?
  - a) How was Primary school?
  - b) Was Primary school more or less including/accepting/friendly for you?
  - c) Do you think the way adults in school treat you affects the way that other young people treat you? a) In what ways?

- 4) What would you change, if anything, about how you are treated, spoken to by adults or other young people?
  
- 5) How involved do you feel, if at all, in any decision making about your experience of school?

## **Semi-structured Interview Questions**

### **Young People's Questions**

- 1) Have you ever been involved in a school council?
  
- 2) What sorts of activities would you like to do with friends in school?
  - a) Cooking?
  - b) Art work, clay, painting?
  - c) Gardening?
  - d) ICT?
  
- 3) What sorts of activities would you like to do with friends out of school?
  - a) Cinema?
  - b) Art work, clay, painting?
  - c) Gardening?
  - d) Clubs or Sports?
  - e) Games PS2 X-Box etc.
  
- 4) What would you like to do in the future?
  - a) After finishing school?
  - b) College and courses?
  - c) Work?
  
- 5) How close do you like TAs to stay to you?
  - a) How does this make you feel?

- 6) How close do you like friends to stay to you?
  - a) How does this make you feel?
- 7) How safe do you feel at school?
- 8) How happy are you?
- 9) What makes you feel happy?

## **Additional questions for semi-structured interviews.**

1. What is a friend?
2. How do you know that someone is your friend?
3. What do you understand by 'having a sense of belonging'?
4. What makes you feel that you 'belong' at this school?
5. What makes you feel that you 'belong' in this community?
6. How could school get better at helping you feel that you belong?
7. How could the community get better at helping you feel that you belong?
8. What barriers to belonging do you experience at school?
9. What barriers to belonging do you experience in the community?
10. What else is important to you about friendship and belonging?

**Appendix 8**

**Questionnaire for Pupils**

a)

1	2	3	4	5	6	7	8	9	10
I have lots of friends at school							I have no friends at school		

b)

1	2	3	4	5	6	7	8	9	10
I often see my school friends out of school							I rarely see my school friends out of school		

c)

1	2	3	4	5	6	7	8	9	10
My TA often helps me make friends							My TA never helps me make friends		

d)

1	2	3	4	5	6	7	8	9	10
I feel included in a group of friends at school							I feel excluded from having a group of friends at school		

e)

1	2	3	4	5	6	7	8	9	10
I feel valued as a member of class at school							I don't feel valued as a member of class at school		

**Appendix 9**

Eliciting the views of disabled young people on friendship and belonging.

Action group evaluation comments

Name (optional)..... Role.....

Other comments: Pre group sessions
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Other comments: Post group sessions
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## Appendix 10

### Example of Grounded theory data analysis

#### Qualitative codes and their definitions

Table 4. Example of concept coding from Chris's semi-structured interview data

Conceptual category	Focused coding	Initial code descriptive	Data
Feelings	Unhappiness	Unhappy at previous school.	Chris: Elmside Mainstream  <i>"Obviously I wasn't too happy with my last school and that was a down part of my school life and that but here's brilliant. I was really low on confidence at my last school anyway but Elmside has done so much for me. They're the ones that got me introduced to wheelchair tennis and they're the ones I've got to thank for getting there and meeting all my new friends. They've helped me a lot confidence wise.</i>
Confidence	Lack of confidence	Here's brilliant	
	Disability sport	School introduced	
	Built confidence		
Empowerment and agency	Extended social life beyond school	Wheelchair tennis helped meet friends and build confidence	
Competency and choice	Mixing of groups of friends	See friends out of school with similar interests	
Social opportunities	Range of accessible social opportunities	Different groups of friends meet up and merge	

## **Appendix 11**

### **Responses to the question, 'how important are friends to you?' from transcripts**

*"A lot, very important. Well me and Rose are just really good friends, and it's really, really lovely, yeah."* (Robbie, 16, Specialist setting)

*"Socially it means a lot to me. I get on well with everyone so even if you don't like the lesson when you've got a group of friends that you know you can sit there with and joke about with and have a good time in the lessons as well as learning stuff. If you don't have friends in a lesson you feel sort of a little bit insecure because you don't have anyone to talk to and that. And that gets a bit weird so it's good to have friends with you in lessons."* (Chris, 17, Mainstream)

*"Important because if you're like bullied they can help you out of it. Yea, my friends like helped me out of it. What happened was, this boy kept on annoying me all week and then my friends actually said something to him and then he like stopped. And me and the boy actually made friend and we're still friends."* (Billy, 13. Mainstream.)

*"Very important really. I speak to them a lot, they help me a lot, all that stuff."* (Elvis, 16, Specialist setting)

*"Very, very important. I just make sure I always have friends with me! I like to be very social and the TAs realise this and they realise it's important they get along with my friends too."* (Lara 17, Mainstream)

*"I mean, for me personally, and this is probably just one of my values more than anything else, but it always goes for me, family, friends and then myself, because I feel that, not necessarily every friend you have, but without the support of certain friends, I would find it quite difficult to sort of talk to people, because I mean, my best friend, I met her in year 9, when I joined the school. And she sat next to me in my English class and in my History class and at first I didn't talk to her, because you don't. You just sort of think, do the work, get on with it. But then I started talking to her and you know, she's like my right arm now. So I think it's really sort of important to have friends, yeah."* (Keira, 17, Mainstream)

*"The ones I have and the ones I find it quite strenuous to keep are really quite important, because I have so little anyway, I only have like one here that if I don't keep that one, I'll be alone again I suppose."* (Jackie, 16, Mainstream)

*"Very important to me because Lucy's and Jenny's friendship is very important because we're best friends and we look out for each other and we stick up for each other as well. And if someone is worried, we like ask them what's wrong and just look after them and listen to what's troubling, see what's on their mind and what's the problems. If anyone's got any problem with Lucy, me or Jenny, one of us three, if we've got a problem with each other, then we got to tell our problems and then we get over it together."* (Rose, 16, Specialist setting)



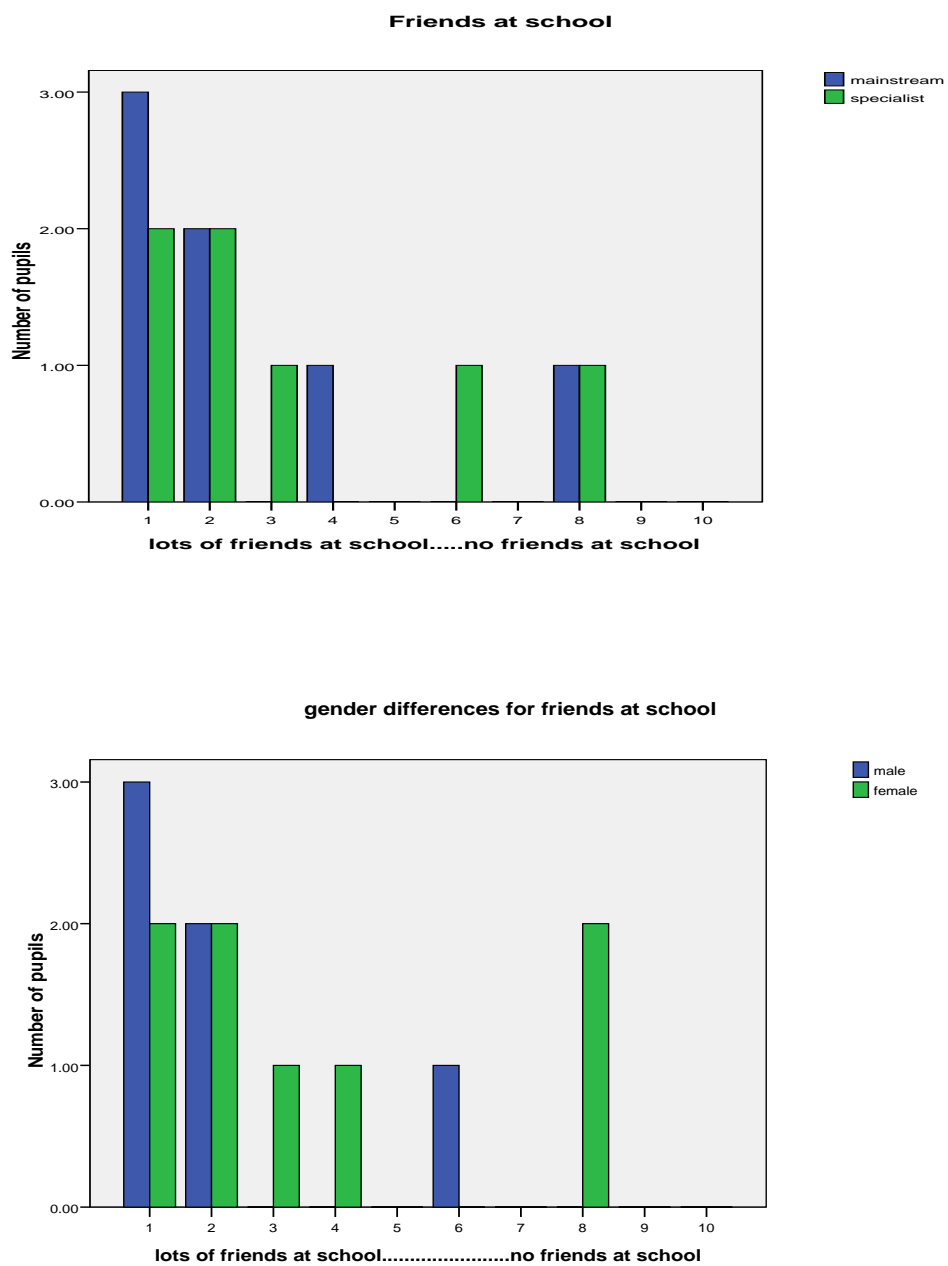
## Appendix 12

### Quantitative data from paper one

Graphs showing a small amount of quantitative data gathered within an interpretive framework using a simple scale-based questionnaire.

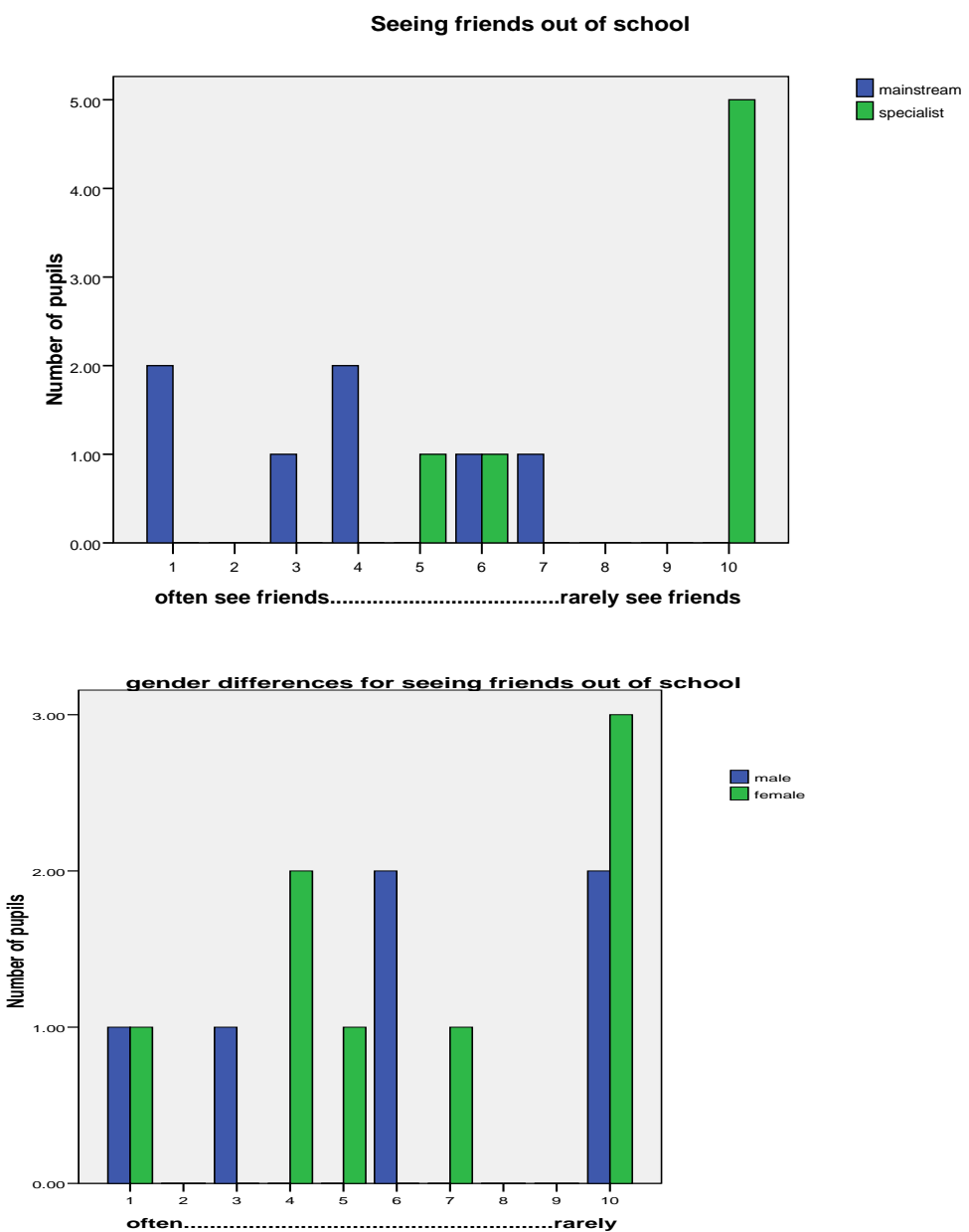
Graphs are analysed showing differences between mainstream and specialist settings and then differences between male and female participants.

Figure 1. Graph showing participants' perceptions of amount of friends at school



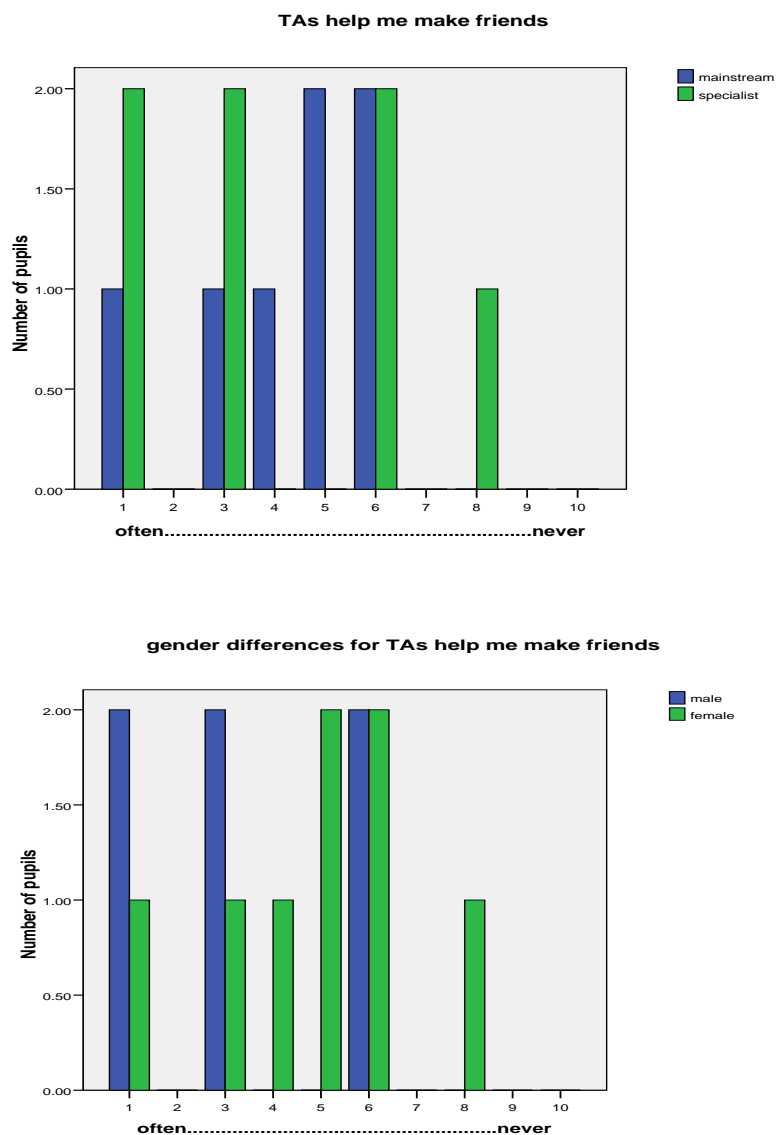
Most participants rated themselves as having lots of friends at school (10 out of 14 rating themselves between 1-3) and only 2 participants rated themselves between 8-10 and both stated that 8 meant having 'a few friends'. Of these 2 participants both were female, one in mainstream and one in a specialist setting. Of the 10 rating themselves as having lots of friends 5 were mainstream and 5 were from specialist settings.

Figure 2. Graph showing participants' perceptions of frequency of seeing friends out of school.



Seeing friends out of school showed the biggest difference of the questionnaire between the mainstream and the Lakeside participants in that 5 out of 7 Lakeside participants rated themselves 10 out of 10 as rarely seeing friends out of school and no mainstream pupils rated themselves as rarely seeing friends out of school. There were no significant differences between male and female participants.

Figure 3. Graph showing participants' perceptions of frequency of help by TAs in making friends

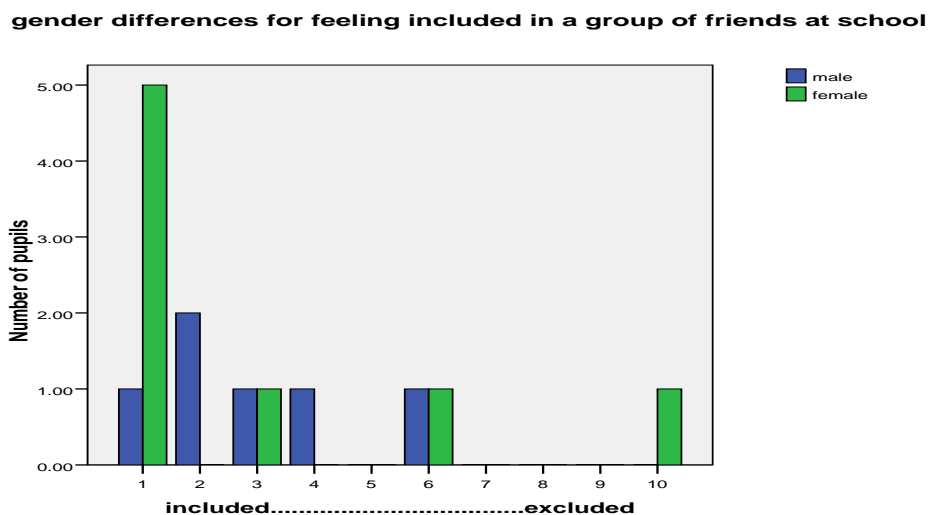
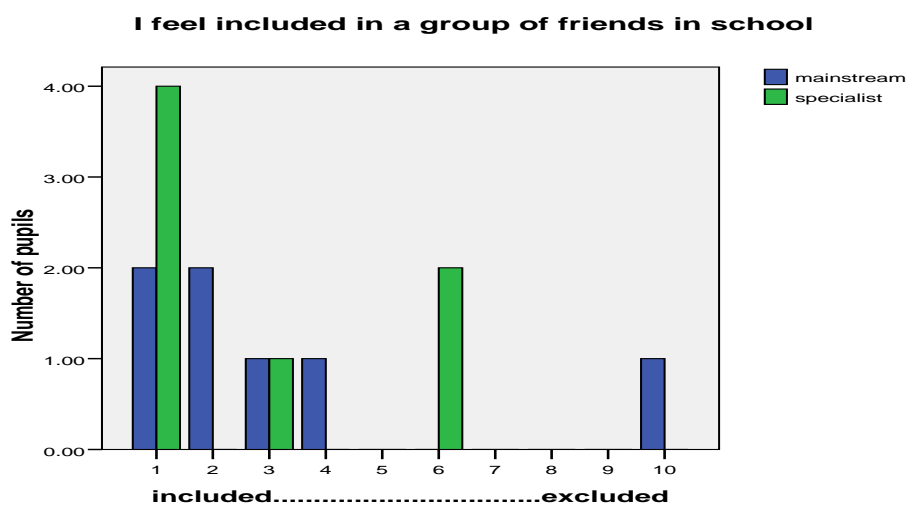


4 out of 7 Lakeside pupils felt their TA often helped them make friends (1-3 on the scale). 2 out of 7 felt that this happened sometimes (6 on the scale) and one person chose an 8 and said this was 'not very often' but that she 'didn't need them to'.

Only 2 out of 7 mainstream pupils felt their TA often (1-3 on the scale) helped them make friends with the remaining 5 out of 7 feeling that this didn't happen often but again stating they didn't think this was needed. No mainstream pupils felt their TAs never helped them make friends.

The gender differences show that 4 out of 6 males said that their TA often helped them make friends whereas only 2 out of 8 female participants said this. 5 out of 8 female pupils said that TAs sometimes helped them make friends and this was discussed in further detail in the semi-structured interviews.

Figure 4. Graph showing participants' perceptions of feeling included in a group of friends at school

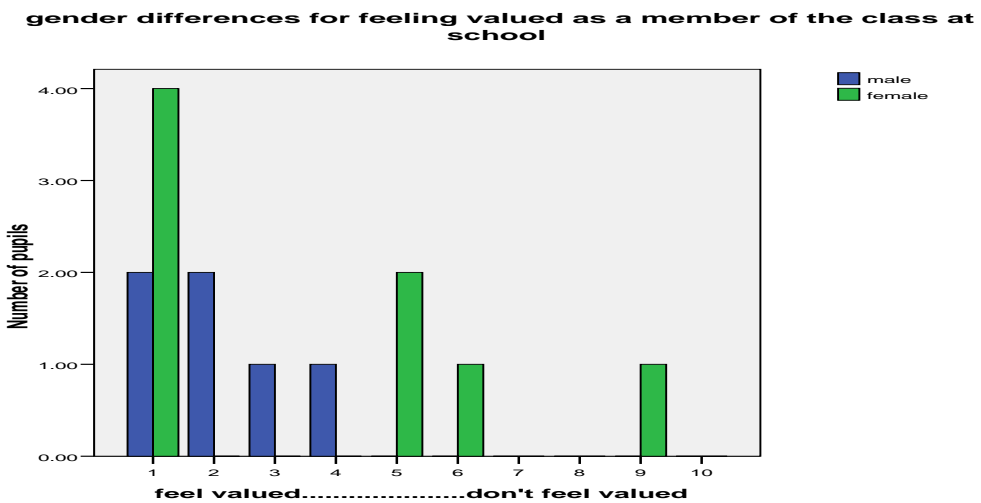
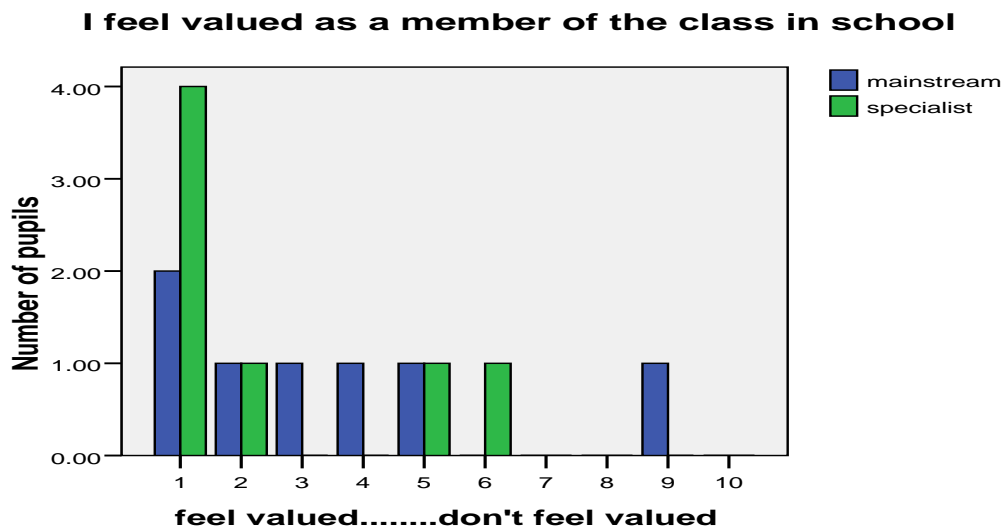


5 out of 7 Lakeside pupils felt included in a group of friends at school. 1 felt 'equal' about it (6 on the scale). No Lakeside pupil felt excluded from having a group of friends at school.

5 out of 7 mainstream pupils felt also included in a group of friends at school 1 felt 'quite included'(4 on the scale) but one (Jackie) felt excluded to the point of 10 and spoke of this in detail in the semi-structured interview.

6 out of 8 female pupils said they were included in a group of friends at school (1-3 on the scale) but 1 female pupil (Jackie) felt very excluded at the point of 10 on the scale.

Figure 5. Graph showing participants' perceptions of feeling valued as a member of the class in school



5 out of 7 Lakeside pupils said they felt valued as a member of the class at school (1-3 of the scale) with none saying they don't feel valued.

4 out of 7 mainstream pupils said they felt valued as a member of the class at school (1-3 of the scale) but with one (Jackie)

saying she didn't feel valued (9 out of a possible 10 on the scale).

5 out of 6 male pupils said they felt valued as a member of the class at school (1-3 of the scale) with one saying he did feel valued at 4 on the scale. The female pupils experienced a wider range of feelings. 4 out of 8 felt valued at the highest point of 1 on the scale. 3 reported they felt 'quite valued' at 5 and 6 on the scale. 1 (Jackie) saying she didn't feel valued (9 out of a possible 10 on the scale).

## Appendix 13

### Discussions data from action research groups

Discussion comments and field notes written by participants based on reactions to the vignette 'A room of our own' by Lara (Appendix 2, p.149) include

#### Uplands:

- *Our experience at this school is reflected by this scenario (TA)*
- *Trust is shown in the pupils and their ability to manage the situation (PSA)*
- *This setup demonstrates a level of responsibility that can be built on and this is shown from Y7 upwards not just VI th form. (SENCo)*
- *I feel and hope that our provision is more like the positive scenario described in that all friends are welcome, disabled, additional needs or non-disabled.....children get together for warmth and a nice space not cos they need to or are made to. Some disabled YP choose not to use the support room and they are free to do so.(Assistant SENCo)*

When invited to talk to some YDP in their setting before the next session the Assistant SENCo and SENCo decide to talk to some of the young people about what they feel about the use of rooms, what changes they would make if any.

#### Oakwoods:

**Deputy Principal** *'This is challenging. It's interesting isn't it getting that balance isn't it between meeting their needs and also supporting their personal development. Do they all want that or might some want to have a space with more adults? Our students have access to different rooms, their tutor room or student support.'*

When invited to talk to some YDP in their setting before the next session the assistant SENCo , TAs and parents decided to talk further to young about social networking. The Deputy Principal and Assistant Head felt that talking to young people may be problematic as they felt the young people would not like to be viewed as different. We agreed that discussion should be informal and voluntary but I suggested that the young people in my research so far had actively chosen to talk about these issues but that I trusted their professional judgement to decide what approach was appropriate in their setting.

### **Lakeside:**

- *It's clear this young person wants a choice of where to go at breaktimes. (TA)*
- *In our school their life experience is so limited that they are unable to make informed decisions or choices.(residential care manager)*
- *Choice is a difficult concept. Young disabled people in a special school setting are often structured to the point where they are unable to make any choices without prompting and permission.(Deputy Head)*

Discussion comments by participants based on reactions to the vignette 'Social networking' by Rose (see Appendix 3, p.150) include

### **Uplands:**

- *Usually for teenagers there is ownership of the friendship without having to get the parents to organise it all the time. In this school it is child →child but in this vignette it is Child →parent →parent →child (SENCo)*
- *Using social networking is really important because you are just you - no disability. It is easier to communicate for disabled people (Assistant SENCo)*
- *Friendships in this vignette are being managed by other people (SENCo)*
- *But safety is a big issue isn't it. Like on Facebook the rule that you have to be 13 is put there for a reason.(TA and parent)*
- *Exactly! I am still the boss. This is my, this is what I feel, Facebook put the rules there for a reason don't they? They don't put the rules there so you change your child's date of birth so they can get on Facebook. And when he's 13, he can go on Facebook and he can put his real date of birth in, until then he doesn't go on Facebook. And I put the setting so high, on his computer when I set it up for Wi-Fi, I can't even go on the Virgin home page!! So I had to turn the settings down just a tad. So yea (TA and parent)*

### **Oakwoods:**



- *My son doesn't use social networking much. He uses Xbox and Playstation 3 and plays with lots of friends online but he also goes swimming and sees friends there.(parent)*
- *We live a long way away from school so talking and playing games on line is really important to him. Once he's on xbox I know he's safe and I know who he's chatting to. He does go on facebook but he's only allowed on it when I'm on it so I know who he's chatting to. So I know he's safe....but now he's allowed to use facebook he's not that interested. The novelty's worn off!(parent)*

#### **Lakeside:**

- *Our children are even more vulnerable than those in mainstream.(TA and inclusion co-ordinator)*
- *This YP was constantly seeking permission which is good... that they knew they needed to check this out first (TA)*
- *Unusual to seek that much reassurance...for a teenager (Deputy Head)*

Discussion comments by participants based on reactions to the vignette '**wheelchair tennis and friendship**' by Chris (see Appendix 6, p.153) include

#### **Uplands:**

- *I used to work in a special school and the children go in a taxi at the end of the day, they go back to where they're living. They don't know the child next door. They don't know that somebody in the same cul-de-sac is having a party, because they don't, and the children living in the cul-de-sac know that child goes to another school in a taxi look. So the social inclusion, it doesn't happen as well. (SENCo)*
- *It's lovely to hear from the children's point of view as well, through the vignettes and comments from other students, because I've put on the evaluation form that I think I know quite a lot about it, but actually, there's a lot I don't know about it. Because we're not living that life!" (TA)*

#### **Oakwoods:**

- *He says he's more confident now and the sport has helped him make friends. (Assistant SENCo)*

- *I wouldn't have thought of that part of the sport....that it would help them build friends....just the sport part I think (TA)*

#### **Lakeside:**

- *At school most would seem to regard their classmates or transport pals as friends but have no particular friend (TA)*
- *Forming friendships can be particularly hard on a practical note as so much of their day is organised by adults. Even a 20 minute break time most of that is taken up with toileting and snacks. 1 hr dinner break, 30 mins dinner, 10/15 mins toileting. May only leave 10-15 mins for them to do as they please. Then a manual wheelchair user would rely on an adult to take them to see their friend. (TA and inclusion co-ordinator)*
- *I think friendships- what we call friendships- are very rare here. For numerous reasons, time, opportunity. (TA)*
- *Young people in special education are very protected in home and school. They may only socialise with family members at home” .(residential care manager)*
- *Young people who attend a special school often have more complex physical and medical needs, which has necessitated intense attention given to their intimate and personal care. Often from tiny babies their entire existence has been adult orientated. Because of this they have been through necessity protected to the point where they have never developed a coping mechanism for mixing and making friends with other young people (Deputy Head)*

#### **Rights and responsibilities**

##### **Uplands:**

*“Before this action research group, I was thinking where I am to do with physical disability, because my mother was physically disabled, so I grew up being really feisty, how dare you not have a ramp?! And one of my kind of thoughts, actually is I need to take, not two steps, but a step back and think, what does that person want? Because I'm automatically fighting for their rights, and that may not always be what they want. I mean I don't go and say, this person here, we want that, don't embarrass people like that, but you know, chatting to Keira, she's quite happy with most things that*

*happen. Things like when she was going for 6th form, she wanted there to be a Stannah stair lift on the stairs, to go up the stairs and the first meeting we went to, they were saying, well it's really expensive, what we'll do is we will move the classes downstairs. And I spoke to her, I said, how do you feel about it? Well, she said, I want to be able to go upstairs with my friends. So they put a stair lift in, because that's what she wanted. And so it was totally, your action in, happening around what she wanted, because yes it would be cheaper and more convenient if you like, to move everybody else downstairs, but there was, being in the 6th form is all about being independent, not being managed." (SENCo)*

### **Uplands:**

SENCo Well I get parents coming in here for your ten eleven year old children, on transition, who haven't applied for DLA because they don't know about it. At least the parents who are seeing doctors, presumably are, you know, I've got a parent coming later on today, who had a meeting about three weeks ago, you were at the meeting of the, and I said to her, who's your paediatrician? She said, oh we haven't got one. We've never seen one. Yet this child's got incredibly complex, not just educational needs but feeding, sleeping, huge impact on and behaviour, huge effect on the family. They didn't know what help that could access and where from. There is great variation isn't there? I mean, I think (?) PSAs being in schools now, is fantastic, because often it's just that information that the parents lack and if you don't know, you don't know that you don't know it.

Parent A Exactly!

Parent A *It wasn't until, I didn't know anything, when Rocco was born he was obviously physically disabled and I wasn't told for two years what I was entitled to. I wasn't given a social worker, I had no help for two years.*

*Yea, that was it. I just didn't have, no-one told me and I was living with my mum and that, you know, just left, until I then thought, do you know, I do want to move out, I do want to get my own home and then I had a social worker. But would I get any help? Not until then, I had nothing. Oh once I got someone to help me my social worker was absolutely fantastic, she was brilliant, but for two years, nothing.*

Parent A *Oh yea, I mean you've always got to fight for everything that you want nowadays anyway, haven't you? Nothing is ever given to you.*

Parent B *I just went and banged on the consultant's door. And he said, you can't do this, I'm in surgery! And I said, I'm here! I'm doing it! And it was sorted.*

Parent A They denied Rocco a wheelchair as well at first, I had to fight for that. We can't go anywhere, he can't walk.

SENCo *You don't know it's there do you? Like you don't know what you're entitled to, know what support groups are around. And I think you can probably just feel more and more isolated.*

PSA *The other thing is, there is a lot on the internet, but you've got to be the right type of person to be using the internet, because recently someone said to me, oh, I can't do that, I don't use a computer. And we automatically assume these days that most people do.*

#### **BELONGING: Difference and being the same**

SENCo *Can I just say, just on this talking about clothing and what other children are doing, our Emma who is here, has always been very very with it with her clothing and very feisty with her hair colour and it's fantastic. And she wants to be like the next person, it doesn't matter that she has a walking frame, Ashley is very much the same, he wants to be like the next lad coming along.*

TA *They're very cool aren't they? They're very image conscious*

SENCo *I'm really, really proud of this school, what we've got in this school, because neither of those kids who are the most disabled kids in the school, they don't feel marginalised. They're in the midst of it, I'm always really proud actually when Rocco gets into trouble, because that means he's just a normal lad.*

Parent A *You must have been extremely proud of him then!*

PSA *That is because they've been put in and allowed to go into mainstream and not been to be different*

#### **Oaklands**

Parent A *In uniform they all look the same, there's no like, oh you know, we know that child is a well-off child or whether that child doesn't get, because they all look the same.*

Parent B *Yea, that's a good point too*

Asst Head *And that's a sense of belonging isn't it, and being like everybody else!*

### **A sense of belonging and inclusion:**

#### **Oaklands**

Parent B *We thought of inclusion in groups who are more socially accepting – my husband came up with that one.*

Claire *Can you give me an example of what you mean by that?*

Parent B *Well I think we've got more of a mix with children that maybe teachers or TAs knew that maybe more accepting with children with a disability or a social disability, whatever, you know, that they could sort of be more, because we've had that with D, that some children who are really accepting what his condition is, what his needs are and other children that just seem to see him as a target, you know, for bullying and what not.*

Claire *So the two sides of that with pupils, that there are some that have got sensitivity and empathy and they're really good to facilitate those friendships*

Parent B *We've found some that are just accepting of the way he is, you know, they just say, you know, it's just D being D and the more, whereas others you know, are not accepting.*

Asst Head *Is that what you think it is then, that they can see beyond the condition and sort of like look at the person without being sort of frightened by or not understanding quite what they see?*

Parent B *And also to know how to make allowances for that person as well.*

#### **Lakeside**

*Young people in a special school are often too compliant. In addition we have those young people who have no accepted form of communication and they have to rely on communication aids. This takes a long time for the YP to say what they want to say and often by the time they have managed this task the person they were talking to has got fed up and walked away. When this happens time and time again it is no wonder that the young person gives up and doesn't even try to communicate anymore. This can*

*appear as the young person not having any ideas or opinions when in fact they have just given up on hoping that others are interested in what they have to say .(Field notes by residential care manager)*

### **Evaluative comments from 3<sup>rd</sup> session**

#### **Uplands**

*My mind keeps going back to that young lady in the first vignette, where she was saying about she wants to be able to email her friend, who's only in the next classroom. And my mind keeps coming back to that, and I keep, that's the one thing that stuck and I keep thinking, you know, they've got, not just of this group of disabled students, but all of our kids, we're looking after, they've got the time to do that, and even this morning, I said to a group, go and take the key, go next door and play that game. Take whichever friend you want to go in, because that, we call on our computer at break time, as our own space when we first kind of session.*

*They love it, they know we're there if they need us. I've just, there was a lady who was always on duty at break-time, I've just stood her down and said, you don't need to do this anymore, because we're in one room, not with the children, but we're there if they need us. And the other room is un-supervised, but we're just there next door if needed.'*

*I know it's been really useful for parents to come in and talk about things, and we'd like to take this up as an ongoing thing, with other parents of disabled students, from September. To actually have a regular group meeting and just to talk about issues, about inclusion.'* (SENCo)

#### **SENCo**

*'I am very pleased to have had the opportunity to just sit and hear directly from the young people about their experiences of social inclusion and exclusion. We have changed our practice as a department and it has made us more aware of seeking to make as much as possible a 'normal' teenage environment for our physically impaired students.'*

#### **Parent Support Adviser**

*'it's been good reflective practice experience to see others perceptions of the school and its practices and facilities offered to all students.'*

#### **T A/parent**

*'made me know how to treat my own son!! And how different we all are xx'*

#### **TA/parent**

*'I want to find out where parents would find out more about social events SEN children could be included in. How the information could be made more available.'*

**Parent of a young disabled person (Rocco)**

*'Before I always thought I knew what my son wanted and needed but now I have listened to what he feels and wants and have understood a lot more.'*

**Assistant SENCo**

*'I feel more confident about how disabled young people feel about a variety of social inclusion issues since specifically taking time to discuss options with them.'*

**Oakwoods:**

**Parent of a young person with additional needs**

*'these sessions have been very informative. I found it useful to hear views from other parents, teachers, members of school staff. It also encouraged me to discuss topics discussed with my son.'*

**Parent of a young disabled person**

*'I have found these sessions useful as it has made me stop and think about where my son is and has led to more in-depth discussion with him about how he sees himself within the school environment. Something I don't think I would have done otherwise.'*

**Deputy SENCo**

*'The importance of talking to students has been highlighted. Having time dedicated to thinking about these issues has been very worthwhile.'*

**Teaching Assistant**

*'interesting to hear views of other schools along with parents of our own pupils. Do not always get to hear what the parents think as a TA working with their offspring.'*

**Assistant Headteacher**

*'Very useful sessions. We are due to review our inclusion policy and we would like to include parents in that process and what we have been discussing in these action research groups.'*

**Lakeside:**

### **TA/inclusion co-ordinator**

*'I thought I had more understanding of general needs of the young disabled I knew. I felt some understanding in this area was lacking. I was surprised to realise my understanding was less than I thought. Some very good points were raised. I hope the school gets a copy of the outcome as I think it would be a useful place to start with changing things.'*

### **Deputy Headteacher/ former outreach teacher for physically disabled children)**

*'Questions to make me think! I am finding out more about the emotional needs of our pupils and have realised how much there is to learn. Questions to make me think! Most of our children welcome the opportunities for inclusive social activities but others appear to be very frightened of the thought. This can be seen in our pupils from quite an early age (before 10 years old). I welcome the inclusion of more therapy work at school and feel that joint training with teachers, TAs, mainstream, parents, carers would be very valuable to help us with the understanding of emotional development/intelligence which could support the inclusion of our pupils more successfully both at home and at school.'*

### **TA/mealtime assistant/parent**

*'I have learnt not to presume I know but to ask more. Not all young people are the same. We need to have discussions with pupils about their free time and find space they want to use.'*

*I have really enjoyed the time I have spent with Claire and the group. It has really made me think more about what we offer our students in terms of their free time and inclusion. We need to look at how we can offer the students their own space to socialise and give them some free time to do this.'*

### **TA/ nursery assistant**

*'I think these sessions have really made me think about what the children think/feel. I think this has opened my eyes to the difficulties they may face with social relationships and friendships. I have found it particularly useful and interesting to share views with colleagues. The sessions have given me more of an insight into how difficult it can be for our children to integrate with mainstream children and I think I will be looking for ways to improve this with the children I work with in the future. Even though the sessions featured the issues of older children more I still think there are lessons for those working with the younger school members.'*



## **Appendix 14**

**Ethical consent was obtained from the University of Exeter Ethics Committee and submitted with this thesis.**

## Appendix 15

### CONSENT FORM FOR PARTICIPANTS

#### Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.

I have been fully informed about the aims and purposes of the project.

I understand that:

there is no compulsion for me to participate in this research project and, if I do choose to participate, I may at any stage withdraw my participation

I have the right to refuse permission for the publication of any information about me

any information which I give will be used solely for the purposes of this research project, which may include publications

all information I give will be treated as confidential

the researcher will make every effort to preserve my anonymity

.....  
.....

(Signature of participant )

(Date)

.....

(Printed name of participant)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s)

If you have any concerns about the project that you would like to discuss, please contact:

Claire Hoskin

Trainee Educational Psychologist

Psychology Service

Tel no

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonymised form.

## CONSENT FORM FOR YOUNG PARTICIPANTS

Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.

I have been fully informed about the aims and purposes of the project.

I understand that:

there is no compulsion for me to participate in this research project and, if I do choose to participate, I may at any stage withdraw my participation

I have the right to refuse permission for the publication of any information about me

any information which I give will be used solely for the purposes of this research project, which may include publications

all information I give will be treated as confidential

the researcher will make every effort to preserve my anonymity

.....

.....

(Signature of participant)

(Date)

.....

(Printed name of participant)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s)

If you have any concerns about the project that you would like to discuss, please contact:

Claire Hoskin

Trainee Educational Psychologist

Psychology Service

Tel no

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonymised form

Appendix

## CONSENT FORM FOR PARENT OF PARTICIPANTS

### Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.

I have been fully informed about the aims and purposes of the project.

I understand that:

there is no compulsion for me to participate in this research project and, if I do choose to participate, I may at any stage withdraw my participation

I have the right to refuse permission for the publication of any information about me

any information which I give will be used solely for the purposes of this research project, which may include publications

all information I give will be treated as confidential

the researcher will make every effort to preserve my anonymity

.....

.....

(Signature of participant's parent)  
(Date)

.....

(Printed name of participant's parent)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s)

If you have any concerns about the project that you would like to discuss, please contact:

Claire Hoskin

Trainee Educational Psychologist

Psychology Service

Tel no

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonymised form

## **Appendix 16**

A research project...

### **Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.**

#### **Aims and purposes**

I am a Trainee Educational Psychologist working for the Psychology Service which uses a collaborative approach to work with children, families and schools. I am undertaking this research as part of my Doctorate in Educational, Child and Community Psychology with the University of Exeter.

This research involves talking with and, most importantly, listening to the views of disabled young people about their experiences of friendship and belonging in mainstream and specialist schools. I am interested in what opportunities disabled young people feel they have to make positive relationships with adults and peers, how important these relationships are to them and how do they think adults can facilitate their experience of friendship and inclusion.

To do this I will listen to the views of the young people participating in this research using a semi-structured interview methodology. I will also ask them to fill out a simple scale-based questionnaire about how they feel about friendship, their experiences of how Teaching Assistants have supported them developing or maintaining friendships and how far they feel valued as part of their class.

The views and materials I gather from these individual discussions I will anonymise and use as a basis for action research projects with groups of parents, teachers and TAs. These will explore how we can use these views to reflect on and improve our practice of supporting disabled young people. We will also consider the opportunities parents, teachers and TAs have to develop, in their own settings, opportunities to listen to the views of disabled young people. We aim, therefore to gain further insights into how to enable these disabled young people to feel fully included and successful in their friendship groups and school communities.

This research will be published in the form of two papers (articles) for professional psychology journals. All content will be anonymised and the content will be fed back to the participants before publication. I fully abide by the BPS Code of Ethics and Practice (2006) in all aspects of this research which state that all participants must offer their informed consent and have the right to withdraw from the research at any time. For further detail please see the informed consent forms attached to this research project information. This research takes place in a context of increased legislation promoting inclusive schooling and a commitment by Psychology Service to support inclusion and participation for all pupils.

If you would like to discuss the project further or participate in this research please contact:

Claire Hoskin

Trainee Educational Psychologist

Psychology service

Tel no.

## **Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.**

### **Aims and Purposes**

This research proposes a two-stage research project within a paradigm of social constructionism using a grounded theory methodology.

Firstly, eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings using in depth semi-structured interviews and a simple scale-based questionnaire.

Secondly, using the views gathered from the disabled young people to disseminate these individual authentic voices to groups of teachers, teaching assistants (TAs) and parents in 3 action research sessions. Vignettes of these views will be used as a stimulus for discussion to develop a greater understanding of the experiences of these children leading to possible changes in practice or further opportunities for social inclusion both in school and in the wider community.

These 3 group sessions will take the form of action research discussion groups rather than INSET presentations to allow the collaborative development of understanding, ways forward and the development of a conceptual framework between all the members of the group. This values the insights and experiences of school based professionals and parents or carers in developing ways of listening to, including and encouraging participation of disabled young people.

The questionnaires from the semi-structured interviews and the pre and post INSET evaluations will provide a small amount of subjective quantitative data which will be analysed descriptively.

This research takes place in a context of increased legislation promoting inclusive schooling but with an awareness of government agenda to raise standards and measure academic achievement outcomes for schools which may discourage schools from making the 'required adjustments' to ensure full social inclusion and participation for all pupils.

## **My research questions are,**

4. What opportunities do disabled young people feel they have to make positive relationships with adults and peers in mainstream or specialised settings?
5. Why are friendship and a sense of belonging important for disabled young people?
6. How can we, as educational professionals, learn from the 'autobiographical voice' of these young people to improve the development of their friendships and sense of belonging to enhance their experience of social inclusion?

## **Possible themes identified so far**

- **The importance of friendship**
- **The role of the TA in social inclusion**
- **A room of our own**
- **Disabled sports**
- **Social Networking with friends: barriers and opportunities**
- **Feeling safe**

## **Group discussions: Possible directions**

- 1) Explanation of research project  
Vignettes of young people's views  
  
What do our young people really think?  
  
Listening to young people
- 2) New views: barriers and opportunities  
Rooms: A space to be

Sports: Empowerment, opportunity

Social Networking: letting it happen and E- safety

Other important issues

- 3) Social inclusion  
From school to home and wider community

Staying safe

Conceptual framework

Inclusion questionnaire

If you would like to discuss the project further or participate in the project please contact:

**Claire Hoskin**

Trainee Educational Psychologist

Psychology Service

[claire.hoskin@gov.uk](mailto:claire.hoskin@gov.uk)

tel



## Appendix 17

### Literature Review

This literature review has been marked and examined **separately** from the examination of this thesis. It is appended here for completeness and to give coherence to the whole thesis.

# Doctorate in Educational, Child and Community Psychology D.Ed Psy

## R4

### Literature Review

Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.

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Submitted 7/9/2009

## **Literature Review**

Eliciting the views of disabled young people on friendship and belonging in mainstream and specialist settings.

### **Introduction**

The purpose of this literature review is to inform the aims of this study which are to elicit the views of physically disabled young people on what opportunities they have to develop and maintain positive relationships with others in school settings. It aims to analyse and critique relevant literature on the importance of friendship and belonging and how we, as educational professionals, can enhance these young people's experience of social inclusion and participation.

I will examine and current theory and research concerning inclusion, disability issues, young people's views and peer relationships and I will be hoping to identify the gaps or weaknesses within what is agreed and what is contested. I will also briefly examine a sample the literature on participation and organisational change as the data emerging from the grounded theory methodology that I am employing in this research is indicating that these theories will underpin the second part of my study working with educational professionals.

It is important to me that this research speaks to practice and supports the development of role of the Educational Psychology Service in empowering young people to have an active voice and participate meaningfully in their own educational lives. It also will contribute to the development of the Educational Psychology Service Plan to facilitate, support and sustain active change to underpin school improvement.

In order to achieve a systematic search the following key terms and other related terms were used on the University of Exeter library database, EBSCO and PsychInfo databases.

*Children's views, voice, disabled young people's views, inclusion, models of disability, friendship and belonging, peer relationships, Teaching Assistant relationships, participation and organisational change.* Also key texts that were referenced and cited frequently in relevant research papers from initial searches were also examined. Recent relevant legislation is also reviewed.

The following literature review is therefore organised in the following sections

- My Research Context
- Disability and Inclusion
- Friendship and Belonging
- Young People's Voice

- Participation
- Organisational change

## **My Research Context**

Despite the stated importance of eliciting children's views and facilitating their participation in the decision making processes concerning their education (SEN Code of Practice, 2002, Every Child Matters (ECM) Agenda, 2004, Removing Barriers to Achievement, 2004, Disability Discrimination Act (DDA), 2005) children identified as having Special Educational Needs or 'additional needs' may experience a tokenism in actually being listened to, socially included or enabled to participate in meaningful ways in the educational decisions that affect and concern them most.

Much psychological research focuses on the views of teachers, professionals and parents but rarely the actual stated view of the child themselves. Young people who have additional needs such as physical impairments, especially when coupled with speech difficulties, may find their views are not sought or represented. There may be a fixation on their medical needs, especially a view of the child as 'tragic victim', medical model, rather than an understanding of the socially constructed nature of disability (Swain, French & Cameron, 2003).

I have chosen, in discussion with my participants for this research, to use the term 'disabled child'. I asked my participants if they preferred the terms 'disabled' or 'physically impaired'. All preferred 'disabled' rather than 'impaired'. Being influenced by the 'person first' argument I began my research writing talking about 'children with a physical disability' but as I read more around the issue of medical model and social model of disability I realised that the disability 'belongs' to society *not* to the child and therefore I could either say children with a physical impairment or a disabled child. In respect to the preference expressed by the young participants, and in acknowledgement of the socially constructed nature of disability I, therefore, use the term 'disabled child'.

So children's voice, despite much legislation and positive rhetoric, may be in practice marginalised and the support given to them in mainstream settings may not be what they would choose if they were actually asked. In specialised settings a disabled child may have a greater sense of belonging to a community and a peer group that has a similar cultural set of norms and understandings but is special school provision leading to lower academic and future employment expectations, later stigmatisation and isolation? The dilemma of successful inclusion for all young people, however, moves beyond a simplistic notion of physical inclusion in mainstream settings being unproblematic. The wider social, political and moral dimensions of young people's rights may be overlooked or remain

misunderstood if the disabled child is thought to need to be 'normalised' as much as possible in order to 'fit into' mainstream school. A more respectful understanding of the value of the disabled child as a vibrant and important part of the normal diversity of human beings may, therefore, not be celebrated and acknowledged. O' Hanlon (2003) speaks powerfully about the fragmented and struggling nature of school systems and recognises the challenges inherent within this system of building social capital and social well-being for all pupils. Writing in "Educational Inclusion as Action Research" she asserts that there are 'immeasurable benefits' to be gained from what people give to each other. She counsels that as educators we need to be aware of what young people with special needs, disabilities and cultural differences contribute to a school community. She acknowledges that,

*"this is an under researched area and discussion all too readily focuses on young people's needs rather than their added value to education in specific school communities."*

*(O'Hanlon 2003, p.9.)*

The gap this study aims to fill is a deeper understanding that eliciting young people's views and encouraging participation is not only consistent with espoused government and service aims but that this can be achieved in meaningful ways as a part of both service delivery and research practice. O' Hanlon (2003) asserts that much learning occurs 'between peers and beyond organised lessons'. This research I am hoping will contribute to

promoting a culture that recognises the 'covert rewards' of supporting friendships in an inclusive environment. These benefits often remain 'invisible' and therefore are not often utilised in support of inclusive education and young people's rights (O'Hanlon 2003). This writing is particularly relevant and useful as it highlights the 'invisibility' of disabled children's friendship which will be examined in more detail later.

### **Relevant Legislation**

Despite a professed increasing government commitment to inclusion of pupils with physical impairments in mainstream settings (DfES, 2002, DDA, 2005 , ECM 2004) schools anxieties about league tables and results in the climate of a governmental raising standards agenda may be dissuading some schools from making the reasonable adjustment required for pupils to experience full social inclusion. The literature about inclusion is wide ranging from the functionalist and pragmatic views expressed in government legislation to a much more insightful exploration of the dilemmas of inclusion (Kelly and Norwich, 2004, Thomas and Vaughan 2004, Topping and Maloney, 2004, Norwich, 2008) which acknowledge that inclusion is a politically, socially and morally complex issue. The valuable contribution to the inclusion debate by Norwich and Thomas and Vaughan especially will be examined in more detail in the following section

The SEN Code of Practice (2001) takes account of the SEN and Disability Act (2001) and outlines

- ◆ A stronger right for young people to be educated in mainstream provision
- ◆ A duty for schools/early years settings to provide information to parents about arrangements being made to meet their child's needs
- ◆ The Act prohibits schools from discriminating against disabled young people in their admission arrangements
- ◆ Children with disabilities cannot be treated less favourably or placed at a disadvantage.

Moreover it actively promotes listening to children's views as a means of enabling a responsive inclusive education and ensuring participation.

The 2001 Special Educational Needs and Disability Act is a positive linking of SEN with disability issues which has been argued for by the Disabled People's Movement for many years but often ignored by politicians and professional agencies working with young people in educational settings in the past (Oliver, 1996).

However the weaknesses of this legislation Armstrong (2005) argues, and I would agree, is that whilst it contains many positive acknowledgements of inclusion, children's views being heard and rights to participation, it fails to fully acknowledge the political and social contributors to exclusion such as poverty, class and disability discrimination. This is unhelpful as it



encourages the acceptance of SEN as a 'within child' problem rather than looking at the systemic nature of a culture that labels certain young people as 'special' as they do not fit the norms of the culture rather than truly embracing and valuing human diversity. Therefore, despite the positive steps towards inclusion that this legislation may offer, it remains valuable for the Educational Psychologist (EP) to have a wider understanding of the socially constructed nature of Disability and SEN, namely that it is created by the social relations and power structures in society, in order to inform research and practice more thoroughly.

The ECM Agenda (2004), Removing Barriers to Achievement (2004) and DDA (2005) further appear to strengthen the government's commitment to inclusion. The ECM agenda makes outcomes for young people central to integrated young people's services. Outcomes for young people are specified through aims, targets, indicators and inspection criteria which are grouped around five main areas: Be healthy, Stay safe, Enjoy and achieve, Make a positive contribution, and Achieve economic well-being.

Criteria relating to these key outcomes for young people are becoming embedded into the structures and practices of local authority Children and Young People's Services. The practice and research findings of Educational Psychologists may have a significant contribution to make in ensuring that these positive outcomes are realised and do not remain merely rhetoric.

However, despite all this positive legislation and apparent commitment to inclusion, the reality is that many schools anxieties about league tables and results in the climate of a more pressing governmental 'raising standards' agenda may dissuade many schools from making the 'reasonable adjustment' required for pupils to experience full social inclusion (Norwich, 2008, Thomas & Vaughan, 2004, Topping & Maloney, 2005). It is therefore useful to examine more thoroughly the most influential and current literature on inclusion and disability to recognise the full complexity of these issues.

## **Inclusion and Disability.**

### **Dilemmas of Difference**

The work of Norwich (1999, 2004, 2008) in the field of Special Educational Needs and Inclusion is internationally recognised. The breadth and depth of his research allows a thorough consideration of the complex issues of inclusion.

Writing about the 'Dilemmas of Difference' in 2008 Norwich contends

*“ The basic dilemma of difference is whether to recognise or not to recognise differences, as either way there are negative associations or risks associated with stigma, devaluation, rejection or denial of relevant opportunities.”*

- The identification dilemma – whether to identify students as having SEN/disabilities or not?
- Curriculum dilemma – how much of a common curriculum is relevant to these students?
- Placement dilemma – can appropriate learning take place in ordinary schools or not?

For my research, however, the identification dilemma is redundant for most physically disabled young people as their physical impairments are highly visible. Their identity as disabled may be considered ‘surplus visibility’ (*powerless and marginalized groups challenge the expectation that they should be invisible and silent*, Patai, 1995) nevertheless by some peers, teachers or TAs. The view expressed by one of my participants that she should be ‘endlessly grateful and thanking’ her TAs was, I believe, an example of this ‘surplus visibility’ and an aspect not explored by Norwich. Although this visibility negates the identification dilemma for my participants for many children with additional needs this dilemma is relevant. The disabled child is, however, often unable to remain unidentified as ‘different’ amongst their peer group. It may be that the obvious nature of their physical impairment automatically makes them vulnerable to risks associated with stigma, devaluation or rejection but it would be wrong, I believe, for me to deny or assume this without gaining the views of the young people themselves.

The curriculum dilemma may be an issue for my participants but it would be inappropriate to assume a cognitive deficit due to the identification of a physical impairment. It may be the case however that many children with physical impairments are under-expected of academically due to the disabling views of non-disabled educators.

The placement dilemma, however, is the key dilemma that my research will explore in terms of the friendship opportunities and belonging that disabled pupils experience. A positivist perspective of psychology may find the complexity and dilemmatic nature of Norwich's work problematic but personally I find a positivist view more likely to over-simplifying what remains complex issue. The complexity and depth of the 'Dilemmas of Difference' is valuable as it enables a conceptualisation of conflicting rights within inclusion.

Lunt and Norwich (1999) suggest these rights are

1. A right to participate in an ordinary school
2. A right to participate in an ordinary classroom
3. A right to acceptance and respect
4. A right to individually relevant learning
5. A right to engage in common learning opportunities
6. A right to active involvement and choice in the matter

A consideration of these rights have influenced my research project and underpin my epistemological and ontological stance that inclusion is not

just about meeting a child's needs but is also fundamentally about their right to be heard and to participate.

Norwich (2008) warns us that a 'human rights' or 'justice' view of these rights without a greater understanding of their implications for social justice is simplistic. He cites the work of Gewirtz (2002) who distinguishes between distributional and relational justice. The latter which focuses on the nature of relationships and groups within society is a more common consideration for the EP. The role of the EP, however, may be more effective if a deeper understanding of the political and philosophical debates about justice, social justice and the differences between equality and equity are acknowledged. Although an aim of inclusive education may be to reduce social exclusion there may remain a tension between what is right for the individual and what is right for society.

However I would also argue that individual rights and societal rights are not necessarily in conflict if one is able to adjust one's attitude to diversity and inclusion in terms of the insights offered by O'Hanlon (2003) earlier. That is, we need to celebrate and acknowledge what young people with additional needs have to offer to their school communities, rather than assume that their inclusion is to solely meet needs. In this way research and practice that supports inclusion may be seen as emancipatory and transformative rather than as dutiful.

Kelly and Norwich's (2004) and Norwich and Kelly's (2004) studies exploring the views of children with moderate learning difficulties on labelling, sense of self and bullying are particularly relevant to my own study.

Norwich and Kelly (2004) examined the views of 101 young people with a statement for SEN for moderate learning difficulties and their experience of bullying. A methodology of semi-structured interviews was used and the content analysed thematically using NUD-IST and data was analysed quantitatively using chi-square.

The findings are reported clearly with 65% of pupils expressing mainly positive feelings for their present school and only 4% mainly negative feelings. The context of special educational needs provision is thoroughly addressed and the findings have significant implications for the theory, policy and practice of inclusion.

This is a robust and rigorous piece of research that identifies the themes that were of concern to the pupils. The theme of bullying is one that emerges from the analysis and the insights this research offers on this theme are illuminating. However, what is not recognised as a theme in itself are the positive aspects of friendship that the children report although there are several examples of positive friendship cited in the

views of the children reported in the paper. There may have been further instances in the transcripts of the whole interviews and perhaps adult researchers overlook non-problematic 'friendships' that children talk about and 'miss' the importance and centrality of this for the young people themselves.

This research has similarities to my own much smaller-scale research and supports my belief that my area of research is valuable and relevant. Norwich and Kelly's final sentence, '*this calls for more realism and effort in finding ways of eliciting their perspectives,*' encourages me that I can make a valuable contribution to the development of eliciting disabled young people's views on friendship and belonging and encouraging participation and that this is a worthwhile aim for an Educational Psychologist.

### **Needs and Disabilities: Rights and Opportunities**

The work of Thomas and Vaughan (2004) in the field of inclusion and disability is also valuable. They suggest that the UK Special Education system has traditionally emphasised special 'need' rather than the US system which emphasised 'disability'. They contend that British educators talk of special needs whereas American educators would more likely talk in terms of learning disability. The emphasis on needs they propose is more beneficial as it places more responsibility on the provider and gives more focus on provision to meet that need rather than disability that implies treatment. This is an interesting view but I do not agree with this in terms

of my understanding of disability as a social construct. I would argue that 'trauma' implies treatment, 'disability' implies the social model of 'the disabling society' (Oliver, 1996) that society disables those with impairments with a non-inclusive attitude and barriers to access and understanding. A further exploration of the literature concerning the concept of the medical and social models of disability follows this section.

However Thomas and Vaughan (2004) assert that 'rights and opportunities' are a more useful conceptual framework than 'needs' and argue that a 'lack of dignity and respect is too often associated with "having a need."' This I find a helpful discussion. They propose the concepts of rights and opportunities has moved the discussion away from disability towards a wider interest in inclusive education systems irrespective of their difficulty at school whether it be 'disability, poverty, gender or culture'. This is a useful reminder to EPs that always remaining within the discourse of 'needs and provisions' in line with the SEN Code of Practice (2001) could be limiting our view of the inclusion debate and that therefore it is useful to be mindful of the wider political and social issues of inclusion.

### **The medical and social models of disability.**

In reviewing relevant inclusion and disability literature it is helpful to clarify what is dominant in the discourse of medical and social models of disability.



Thomas and Vaughan (2004) suggest that the medical model supports a view of something 'almost constitutional being wrong with the child' which can be diagnosed, labelled and treated. This model is, therefore, less helpful when considering people and their relationships to the families, contexts and cultures in which they live and learn. A medical model may encourage professionals to consider problems as a 'within child' deficit rather than being located within the school or system. These concerns are especially valid for the EP to consider and for my research it has been apposite to understand and critique the medical model in order to engage with the lived experiences of my participants in their mainstream and specialist settings. For example, for physically disabled young people in school there may be a fixation on their medical needs, a view of the child as 'tragic victim', rather than an understanding of the socially constructed nature of disability.

Mike Oliver (1996) has written and researched extensively on disability issues and he suggests that a more appropriate way of viewing a disabled person with a physical disability is to see the person as having an 'impairment'. He argues that it is society and non-disabled people's attitudes and beliefs that hold the dominant discourse on disability and leading to the 'disabling' and exclusion.

Disability, according to the social model, Oliver (1996) suggests, is all the things that 'impose restrictions' on disabled people. This includes 'individual prejudice' and 'institutional discrimination' from segregated education to excluding work arrangements.

*"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society."*

*(UPIAS 1976, p.14)*

I find the work of Oliver (1996) particularly clear about the social model and he argues powerfully for a new view of inclusion that is politically well-informed and challenging. Oliver (1996) proposes that disability is a human rights issue and a fundamentally moral and political issue of inclusion which requires people to broaden their outlook. It is a failure, therefore, he asserts to see inclusion merely in the narrow terms of 'the quality of educational provision.' Inclusion, he suggests, is a multi-faceted and complex concept and disabled people themselves are articulating a new view of integration. He recognises that the movement away from segregation towards integration is a positive shift but argues that educationalists need to change their views and discourses from the 'old' to

the 'new' set out in the table below before we can truly understand and achieve inclusion for pupils.

Table 1. (Oliver, 1996)

Old views: integration	New views: inclusion
11. State	11. Process
12. Non-problematic	12. Problematic
13. Professional and administrative approaches	13. Politics
14. Changes in school organisation	14. Changes in school ethos
15. Teachers acquire skill	15. Teachers acquire commitment
16. Curriculum delivery must change	16. Curriculum content must change
17. Legal rights to integration	17. Moral and political rights to integration
18. Acceptance and tolerance of young people with SEN	18. Valuing and celebration of young people with SEN
19. Normality	19. Difference
20. Integration can be delivered	20. Integration must be struggled for

I have found this table to be thought provoking and the new views Oliver outline inform my study in terms of a shift in my attitude and discourse. His work inspires me with the commitment to carry forward the views of my participants in order to support and challenge schools to develop an ethos of active listening and participation through organisational change to encourage a valuing of diversity within full social inclusion.

Conversely, however, Skidmore (2004) argues that it is insufficient to only consider the tension between a medical and a social model and argues that the concept of inclusion has been researched and practiced using three different major paradigms of research, the psychomedical, the sociological and the organisational.

It is useful, I believe, to understand the language of medical and psychomedical models as, due to the current statutory systems, resources may be increased with identification of needs or diagnosis but this also may increase stigma and a lowering of expectations of what young people can achieve. However if we do not *appear* to speak or understand the same language as medical model joint-agency colleagues we run the risk of being marginalised or discounted and then the child loses a valuable ally.

The social and organisational models, nevertheless, I believe are the most valuable in understanding the systemic, societal and community nature of

children's lives. The second stage of my research involves working with educational professionals and developing participatory practices in order to transform the views expressed in the first part of my research into impetus for meaningful organisational change. A review of a sample of relevant literature in these domains is undertaken in later sections.

In reality, however, many EPs use a synthesis of these paradigms when working with pupils, parents and schools as they recognise that different young people in different settings have a variety of needs which stem from a variety of causes and one paradigm alone is insufficient. The flexible and reflective EP, I believe, will work with a variety perspectives and epistemologies. An awareness of psychological and social paradigms, and how these beliefs and assumptions influence our professional work, is important I believe, if we are to engage in meaningful research and active organisational change.

### **Pupil's own views**

Norwich and Kelly's (2004) studies on the views of pupil's of inclusion and Cook, Swain and French (2001) 'Voices from Segregated Schooling: towards an inclusive education system,' are, I have found, comparatively unusual in

that they directly elicit the views of the pupils themselves on their experiences of inclusion. Cook, Swain and French (2001) assert,

*'much of the research on disability, including disabled children, has ignored the views and experiences of disabled people themselves.'*

This insight is useful and it confirmed by the lack of peer-reviewed research papers that I have uncovered using a key-word search using pupil's voice or pupil's views in psychology databases. Parents and professionals views were often researched but the views of the child themselves, especially in the case of a child with additional needs, are often overlooked.

Robinson and Stalker (1998) confirm this belief

*'whilst there is a well established body of knowledge about the way parents experience life with a disabled child, children's own accounts of their lives are largely missing, their voices have not been heard.'*

In a similar vein Shakespeare and Watson (1998) point out that

*'children can have profound experiences of life, including disability, and yet they have not been consulted or taken seriously by academic or professional 'experts'.'*

These findings are important as they recognise the marginalisation experienced by disabled children and other minority groups when they are not listened to. Therefore by recognising this gap in the literature and by actively listening to the views of physically disabled children as a starting place for understanding their feelings and concerns I hope to contribute to theory and practice in promoting the importance of engaging children in the participatory process in meaningful, relevant and empowering ways.

My research using these autobiographical views obtained as a stimulus for further work to help develop the empathy and practice of educational professionals in the second part of this study but I am clear that I am not saying 'this is how these disabled children feel and therefore this is how the children in your setting will feel.' My role in the second part of the study is to encourage the different settings to value and have the confidence to elicit the views of their own pupils in order to enhance their experience of participation and social inclusion.

This is put most elegantly by a fourteen-year-old boy with a degenerative neuromuscular condition who states,

*"I mean obviously, I want to be treated the same, but then sometimes I'd like to be treated differently...I like to be asked"*

Asprey and Nash (2005)

In this way I am partly drawing on the study by Barrett (2006) who used autobiographical accounts of people with Autistic Spectrum Disorder (ASD) as a stimulus for discussions and empathy development with educational professionals. Whilst Barrett's use of autobiographical materials is powerful I feel that his study is weakened by his failure to engage with actual pupils with ASD in school settings. Also his adapted methodology of discourse analysis is poorly explained and therefore this study is not easily replicable.

Autobiographies such as 'Under the Eye of the Clock' by Christopher Nolan (1987), however, do offer exceptionally moving insights into the experience of a person with cerebral palsy experiencing social inclusion, friendship and academic achievement in a mainstream setting. The use of this and other autobiographies may well enhance the INSET content of my second part of my study but I feel it is valuable and congruent with an ethos of inclusion to mainly draw from the views that participants have expressed directly for this purpose.

## **Friendship and Belonging**

### **Peer Relationships**

My research in exploring the central role of young people's peer relationships in the social development of the child will acknowledge the key role of a sense of belonging and friendship for the development of a healthy pattern of relating to others. This recognises the key influence of



the work of Maslow (1954) and his conceptualisation of a hierarchy of needs. The hierarchical nature of Maslow's needs has drawn criticism but I have found it useful in not losing sight of the safety and belonging needs of children in an era of overwhelming concern about raising educational standards that schools may often define as raising SAT or GCSE level achievement. Although Maslow's work is now 55 years old I feel it remains relevant and has important parallels with the five outcomes of ECM Agenda (2004) and therefore to discount it due to age or over-familiarity would be short-sighted.

The importance of friendship and belonging is also supported by the work of Erikson (1968) which although was first acknowledged four decades ago may still have valuable insights to offer and is still being cited in current texts. This work may be particularly important in adolescence where friendships and peer culture influence a young person's psycho-social development in terms of identity, belonging and sense of self. My research will seek to understand the disabled child's view of the importance of their friendships, and how the development of these friendships can be enhanced or hindered by the actions of the adults working with the child. It may be that adults assume that physically disabled young people either do not have the same need, capability or wish for peer belonging as their non-disabled peers. Or perhaps, through a lack of training, thought and reflection, unhelpful practices that isolate or socially exclude disabled young people have developed in some 'inclusive' mainstream settings.

A study by Dunn and Hughes (1998) investigating young people's understanding of emotions within close relationships critiqued Piagetian assumptions of egocentrism in the young. This raises an important issue when considering development of social competence and that is one of context. Young people are judged competent or incompetent in many different settings but when placed in a natural environment, especially at play with a peer group, we see young people at their full potential rather than viewing them with a deficit model that could be construed as Matusov and Hayes (2000) argue as 'adultocentric'. This is, I suggest, even more acute for the physically disabled child who may be treated as much younger than their chronological age by their carers due to the complexity of their physical needs. These studies are valuable in that they caution the adult researcher to question assumptions and accepted notions about child development and to not underestimate the potential understanding and insights of young people in specific contexts.

Graue and Walsh (1998) counsel, however, that studying young people in context raises methodological questions and a range of ethical issues in terms of informed consent, meaningful context and examining what a child is capable of rather than what they can't do. They suggest there are advantages, therefore, to researchers of interpretive research using a 'grounded theory' approach but this should be flexible. My research offers an important opportunity to recognise the individual and changing nature of a child's peer relationships and by eliciting the views of young people themselves I hope to be researching the actual authentic experience of the

child and not be making assumptions about young people from an 'adultocentric' viewpoint.

The positive role of peer relationships in terms of belonging, friendship and social inclusion and will be explored but the experiences of peer rejection and antipathy will also be recognised as part of the child's lived experience in the social world. Tashie, Shapiro-Barnard and Rosetti (2009) suggest that "from a child's point of view, inclusion at school means having friends.....the uncomfortable reality is that those who appear 'different' are lonely and isolated even in 'inclusive' schools...strategies... will not work without a change of values and some deep thinking about the nature of friendship. The comparative lack of research on friendship that I have experienced in my searches may be indicative of this 'adultocentric' viewpoint that overlooks the importance of children's friendships or takes them for granted rather than seeing them as worthy of study if not problematic.

### **The Role of Teaching Assistants**

Teaching Assistant (TAs ) play an increasing role in the lives of many school children especially those identified as having additional needs (DfES, 2005a). The number of TAs working in schools has doubled since the present Labour Government came to power in 1997 (DfES, 2005b). The concerns of TAs acting unconsciously as a barrier to young people forming friendships are worthy of consideration but there is a significant gap in research literature in this area.

A study by Gerschel (2005) however, does describe the support given by TAs to children with additional needs. She describes TA support as often *'attached to a single student - the 'Velcro' model'* and cites the danger of the child becoming *'emotionally dependent'* on the TA. She also acknowledges that the TA may become a barrier between the pupil and the teacher or peers. She advocates a move to TAs being deployed within faculties working with groups and a *'keyworker'* being named for children to ensure *'vulnerable children know who to turn to'*. This model offers an improvement to professional practice in terms of forging closer working relationships between Teachers and TAs, an improved knowledge of the curriculum and further opportunity to develop support resources available for the TA.

What Gerschel (2005) does not explore in this paper, however, is the view of the child in this situation. Furthermore it is notable that she outlines a comprehensive set of 11 functions for the SENCo; including improving recruitment strategies for TAs, developing skills of teachers working with TAs, developing monitoring and accountability systems for SEN, but does not mention collaboration with the young people receiving the service of TAs and SEN staff. Also empowering decision making skills of students or forums for listening to children's concerns is not acknowledged. The lack of pupil voice or consultation I feel is a significant weakness of this paper which my research will attempt to address in gaining the views of the pupils themselves of the opportunities or barriers for developing and

maintaining friendships that TAs bring as well as their role in academic support.

## **Participation**

My main methodology for my research is grounded theory and one of the initial themes emerging from the data is an interest expressed by many participants is the wish to access all aspects of school and social life including School Council and being a part of interview panels for the recruitment of TAs.

Therefore a research paper that has informed my understanding of the issues of participation is Shier's (2001) *'Pathways to Participation: Openings, Opportunities and Obligations'*. This paper is set in the context of the United Nations Conventions on the Rights of the Child (1991, Article 12.1) and argues that the child's right to have a voice and participate is one of the most widely disregarded provisions in almost every aspect of children's lives. Shier uses Hart's 'Ladder of Participation' (1992) model to clarify the degrees of non-participation (1-3) and participation (4-8) that have traditionally been experienced by children.

Hart defines these as

1. manipulation
2. decoration
3. tokenism

4. assigned but informed
5. consulted and informed
6. adult-initiated shared decisions with children
7. child-initiated and directed
8. child-initiated shared decisions with adults.

Shier rightly acknowledges that Hart's clarification of the false types of participation (1-3) may be the most valuable contribution of this model and one of the strengths of this paper is that it requires us to question the level of child participation we have been promoting as professionals. Shier, in a similar vein, offers an alternative model of participation based on Hart's levels of participation (4-8) which excludes the non-participant levels.

Shier's (2001) model of participation

6. Children are listened to
7. Children are supported in expressing their views
8. Children's views are taken into account
9. Children are involved in decision-making processes
10. Children share power and responsibility for decision making processes

Each of these five levels have three stages of commitment '*Openings, Opportunities and Obligations*'. I have found this model useful in deciding what is practical and workable in my own small-scale study. Although I hope to model and encourage the first three levels of participation in my

practice as an EP I need to consider whether I am able to facilitate a commitment to four and five and also ensure 'openings' at these levels in the first part of my research and 'opportunities' at the second part of my research. 'Obligations' I believe would need to be achieved at the level of organisational change and although in the long term I would aim for this as part of my wider role as an EP and researcher I need to be aware of the limitations of my own study. However it is worthwhile to briefly acknowledge a small sample of the literature on organisational change which does inform both my long term aims and my realistic expectations on what I can achieve with this research.

## **Organisational change**

Georgiades and Phillimore (1975) examined the problems of relying on training as the main strategy for inducting organisational change. The authors drew on evidence from education and industry to assert that attitudes developed in training are often not sustained in the workplace. They suggest that the greatest influence on behaviour is the leadership of the person's immediate supervisor. Therefore "cultivation of the host culture" is key as organisations may "eat hero-innovators for breakfast".

The authors offer six guidelines for achieving successful organisational change (see Appendix 1) and I think it is useful to compare these with the '8 complex change lessons' formulated by Michael Fullan (2003) nearly

three decades later in his book *'Change Forces with a Vengeance'*. (see Appendix 2)

Table 2. A Comparison between the myth of hero innovator and change forces

<b>Complex Change Lessons</b> Fullan (2003)		<b>Comparison with Myth of the Hero Innovator</b> Georgiades and Phillimore (1975)	
1	Give up the idea that the pace of change will slow down.	1	Change will take 3-5 yrs (difference)
2	Coherence making is a never ending proposition and is everyone's responsibility.	2	Work with individuals and groups that have the freedom and capacity to change. (4)
3	Changing context is the focus.	3	build groups, not individuals working in isolation. (2)
4	Premature clarity is a dangerous thing.	4	Avoid premature evaluation of the group (6)
5	The public's thirst for transparency is irreversible.	5	No mention of public (difference)
6	You can't get large scale reform through bottom up strategies – but beware of the trap.	6	Ensure you have permission from top management and commitment from near the top management if possible. (5)
7	Mobilize the social attractors – moral purpose, quality relationships, quality knowledge and ideas.	7	Work with the forces supporting change not those resisting it (1)  Work with the healthy parts of the system(3)
8	Charismatic leadership is negatively associated with sustainability.		Myth of the hero innovator



As can be seen the similarities are striking with an exception being that nearly thirty years ago there was little concept of transparency towards the public and that the rate of change is now seen as rapid. It could be that both are right about the rate of change in that change in present society is imposed rapidly but actual change in the attitudes and practices of professionals remains much slower.

Fullan (2003) advocates

- *Start with the notion of moral purpose, key problems, desirable directions,*
- *Create communities of interaction around these ideas.*
- *Ensure that quality information infuses interaction and related deliberations.*
- *Look for and extract promising patterns, that is, consolidate gains and build on them.*

(p.24)

## **Conclusion**

In conclusion a review of the literature that informs this research identifies that whilst there is a large amount of legislation and theory surrounding inclusion, the views of children, especially those with additional needs, on how this may be achieved successfully have not often been sought. The importance and centrality of social relationships with friends has also often been overlooked especially if they are supportive rather than problematic

and, therefore, I hope my research will contribute something new to the practice and theory of listening to disabled children, encouraging participation and facilitating organisational change to ensure social inclusion for this and other often marginalised groups of young people.

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## Appendix 1

### **Georgiades, N.J. & Phillimore, L. (1975) The myth of the hero innovator and alternative strategies for organisational change**

**Guideline 1.** Work with the forces supporting change not those resisting it.

The ability to listen is key, avoid mass training.

**Guideline 2.** Always try to build groups, not individuals working in isolation. The group provides strengths. Locate people with group maintenance and task expertise within the group.

**Guideline 3.** Work with the healthy parts of the system and do not include those who will sabotage change.

**Guideline 4.** Work with individuals and groups that have the freedom and capacity to change.

**Guideline 5.** Ensure you have permission from top management and commitment from near the top management if possible.

**Guideline 6.** Avoid premature evaluation of the group. Enable frequent meetings of the group. Protect group from outside pressure. Arrange visits from outside supportive professionals. Allow individuals to leave the group if they wish to.

## Appendix 2

Michael Fullan (2003) *Change Forces with a Vengeance*

### Complex Change Lessons

**Lesson 1:** Give up the idea that the pace of change will slow down.

**Lesson 2:** Coherence making is a never ending proposition and is everyone's responsibility.

**Lesson 3:** Changing context is the focus.

**Lesson 4:** Premature clarity is a dangerous thing.

**Lesson 5:** The public's thirst for transparency is irreversible.

**Lesson 6:** You can't get large scale reform through bottom up strategies –  
But beware of the trap.

**Lesson 7:** Mobilize the social attractors – moral purpose, quality relationships, quality knowledge.

**Lesson 8:** Charismatic leadership is negatively associated with sustainability.