The school lives of children and young people with a spinal cord injury

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Acknowledgements

Contents

Background to the study

Approximately 1,000 people each year in Britain survive an injury to their spinal cord. The causation of spinal cord injuries (SCI) is very varied. Falls or traumatic accidents leading to a sudden and life-long paralysis such as car and sporting accidents are common causes, but some children are spinally injured from a young age as a result of a virus or tumour on the spine. Other, rarer, aetiologies include those arising from violence, such as gun shots or stab wounds, and birth injuries.

The symptoms of a SCI depend on the severity of the injury but include muscle weakness and spasms, breathing problems, loss of feeling in the chest, arms and legs, and loss of bowel and bladder function. Spinal cord injuries are usually classified into two main groups: tetraplegic and paraplegic. Tetraplegic injuries involve the loss of movements and sensation in all four limbs whereas paraplegic injury involves loss of movement and sensation in the lower half of the body. The extent of the paralysis also depends on whether the injury is complete, or incomplete. If an injury is incomplete, only part of the spinal cord is damaged and some messages still get through. This means that some or all sensation and movement can exist from below the point of injury. If someone has a complete lesion, however, total paralysis will result below the point of injury and there will be no movement or sensation from this level.

Having a SCI will mean having mobility difficulties though these vary considerably. Some people are able to walk a little; some need help to walk with crutches or a walking frame, while others need to use a wheelchair permanently. A spinal cord injury usually affects bladder and bowel control, so children and young people with a SCI may use urology aids such as a catheter or sheath and may need managing this.

Most previous research about spinally injured young people has been medically based and as a result, there is a dearth of research that highlights

the social experiences of children and young people with a SCI. Relevant recent research includes Johnson and Klaas' (2007) study on play and its implications for paediatric spinal cord injury. This American study examined the recreation involvement for 66 children and adolescents with a SCI and found that most activities for children with a SCI were sedentary and homebound. The authors highlighted the need for health care professionals to be aware of the benefits of unstructured play and active outdoor activities in addition to more structured recreation.

Another American study by Shin et al. (2003) focused on the experiences of 46 caregivers of children with a SCI and examined the factors that influenced the long-term adjustment of families of children with spinal cord injury. These factors included family income, social support, the level of education of the caregivers, the level of the child's injury, physical functioning and emotional state. The study concluded that the carers' level of education and family income was negatively associated with the child's level of adjustment. The children's levels of adjustment also affected the emotional and psychological wellbeing of the carers.

Given the lack of social research – especially in the UK – about children and young people with a SCI, this study on which this report is based is a rare and unique contribution to the literature about the experiences of spinally injured young people and their families.

The policy context

In order to fully understand the school experiences of spinally injured young people and the duties facing schools towards disabled children, this study must be placed in the context of British social policy and legislation. The *Children Act 1989* and its guidelines (DH, 1991) was the first piece of British legislation that included disabled children alongside non-disabled children. The *UN Convention on the Rights of the Child,* also of 1989, ratified by the UK in 1991, gave disabled children the same rights as non-disabled children.

Crucial to a study that focuses on the *mainstream* education of children with a SCI, many government initiatives during the 1990s and early 2000s have been underpinned by a belief that disabled children should be included in mainstream activities such as education and leisure. The Department of Health's *Quality Protects* programme (DH, 1998), for example, emphasised the inclusion of disabled children in mainstream services. The *Disability Discrimination Act 1995* similarly stressed that disabled people should be able to access mainstream services. The Act included disabled children's services in Part III (access to goods and services in general) and in Part IV (access to education and associated services, including care and leisure), which was amended by the *Special Educational Needs and Disability Act 2001.* The *Disability Discrimination Act 2005* extended this legislation by introducing a duty on all public bodies, including transport, to promote the equality of opportunity for disabled people.

Accessing mainstream services and activities for disabled children and their families has also been emphasised by *Valuing People* (DH, 2001), the *National Service Framework for Children, Young People and Maternity Services* (DH, 2004) and in the report, *Improving the Life Chances of Disabled People* (Strategy Unit, 2005).

The inclusion of disabled children and young people in mainstream education has been similarly stressed in recent legislation. The most recent, *the Special Education Needs and Disability Act 2001*, enhanced the rights of children with special educational needs to be educated in mainstream schools by placing new duties on local education authorities to provide for disabled students as favourably as non-disabled students.

The social model of disability

As already stated, spinal cord injuries can be caused in a variety of ways and can result in many different levels of physical impairment. We are able to highlight some observations later in the report about the relationship between

the severity and level of spinal cord injury and the quality of school experience. However, as social researchers adopting a social model of disability, we did not set out to explore this relationship specifically. A social model of disability sees disability as socially constructed, in contrast to the medical model, which tends to emphasise the person's impairment, (see Oliver, 1990; 1996; Oliver and Barnes, 1998). The social model of disability is based on the understanding that a person is not so disabled by their medical condition or impairment but by a society that often fails to provide adequate opportunities and facilities to include people with physical or learning difficulties in mainstream life. According to Oliver (1996), the social model of disability:

> "*does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation*"
> (Oliver, 1996: 32).

Report outline

In the next section, we provide an overview of the study's aims and objectives and then describe the methods used to undertake the study. The section about methods includes a description of the sample and the practical and ethical considerations involved in carrying out the research. We then present the research findings, covering areas such as returning to school after the injury and hospitalisation, transitions between schools, accessing the physical environment, peer relationships, the role of the teaching assistant, striving for independence, PE and sport, school trips, partnership working and the importance of attitudes. The final section of the report presents the research conclusions and recommendations.

Aims and objectives of the study

The main purpose of the research was to explore the experiences of mainstream school of children and young people with SCI in order to inform The Back-Up Trust's Schools Project, which has the aim of improving the quality of school provision for children with spinal cord injuries. A secondary aim was to relate these specific experiences of children with SCI to other wheelchair users.

The research study had the following objectives:

1) To provide a picture and an understanding of the current school experiences of children and young people with SCI from their perspective; what have been the barriers or problems that children with SCI in schools have faced and what has alleviated or overcome these? What have been positive experiences for the children and young people?

2) To identify the experiences of some parents and carers of children and young people with SCI; how, from their point of view, has their son or daughter with SCI experienced school? What has helped or hindered them?

3) To investigate and understand the schools' experience of working with children and young people with SCI; what are the main challenges to schools and what helps them work effectively and sensitively with children and young people with SCI?

4) To gather examples of the resources, such as documents or information relevant to children with SCI, employed by schools to prepare for the return of a child or young person with SCI, after their injury and a period of rehabilitation.

Research Methods

In order to address the research aims and objectives, we adopted a qualitative approach. Qualitative methods are capable of generating rich and illuminative data. For this study, the methods used included interviewing children, young people, parents and professionals, and visual and activity based methods, such as asking young people to show us around their school and some photography of aspects of the school environment and useful equipment. These methods will be explored in more detail after describing the research sample.

The research sample

In total we carried out 82 qualitative interviews with children, young people, parents, carers and professionals. The participants were from all areas of England and Wales.

Children and young people

A total of 29 children and young people between the ages of 10 and 18 were interviewed, 15 boys and 14 girls. The following tables illustrate their ages, ethnicity and the schools they attended.

Ethnicity of participants

A bar chart titled "Ethnicity of participants" with y-axis labelled "No." (0 to 25) and x-axis labelled "Ethnicity". Values: WB = 23, Other European = 1, Asian = 3, Black = 2.

Schools attended by young people

A bar chart titled "Schools attended by young people" with y-axis labelled "No." (0 to 18). Values: Primary = 5, Middle/Secondary = 17, 6th form = 5, Independent secondary = 2.
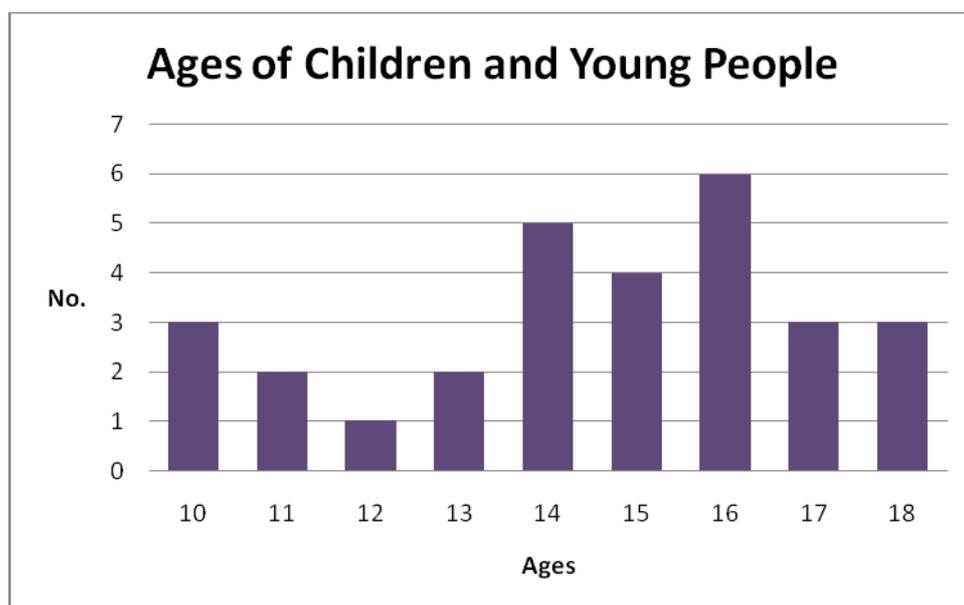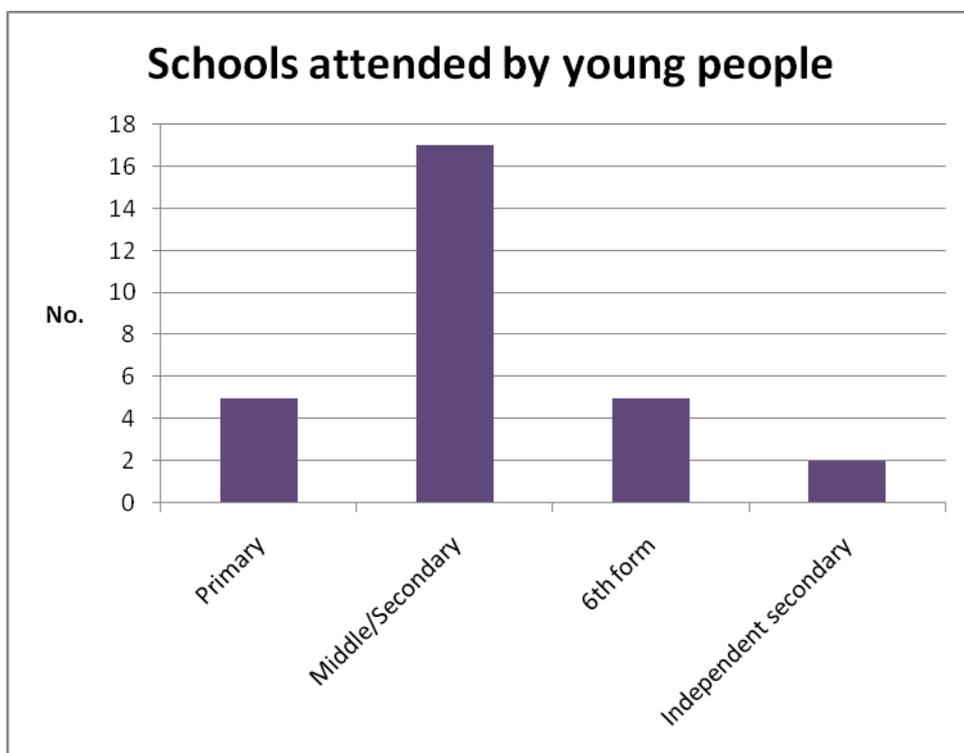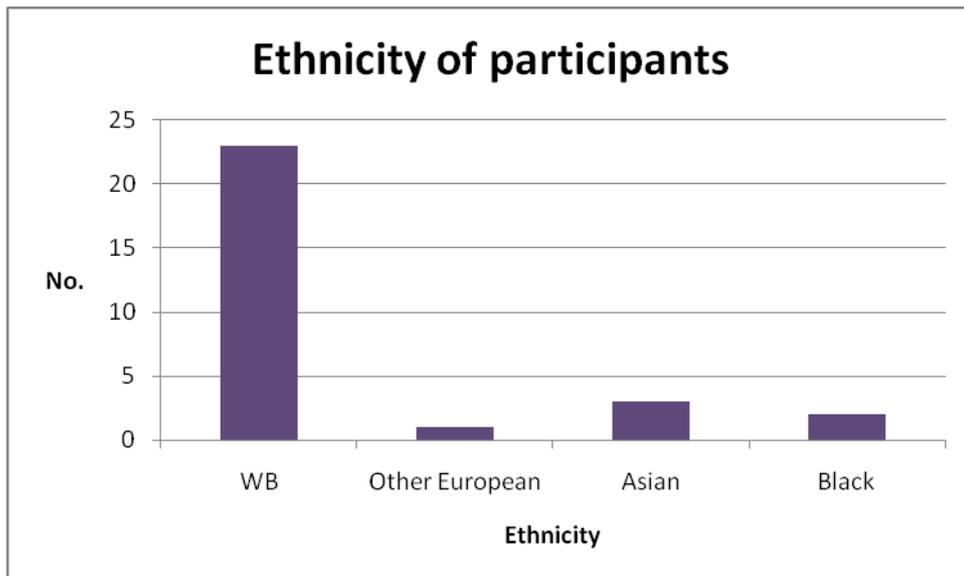
Parents and carers

A total of 28 parents and carers were interviewed for the study. Of these, 24 were mothers, two were fathers, one was a female foster carer, and one was an older sister. All of the primary carers interviewed were the parents or carers of the children and young people interviewed, the vast majority of whom were White British; one was Black African and two were of Asian origin.

Professionals

Twenty-five professionals were interviewed for the study. The vast majority of these were education professionals, including teachers and head teachers, in both primary and secondary mainstream schools. When contacting the young people's schools, we asked to speak to a member of staff who worked closely with the young person, such as a teacher or teaching assistant. We also asked to speak to someone more senior who would be able to comment on issues around the allocation of funding and the school's ethos towards disability, such as a Special Educational Needs Co-ordinator (SENCO) or Head Teacher. A small number (n=4) of 'other' professionals were also interviewed. These were a school nurse, a physiotherapist, a health care assistant and a disability adviser. The table below describes the sample of school based professionals in more detail.
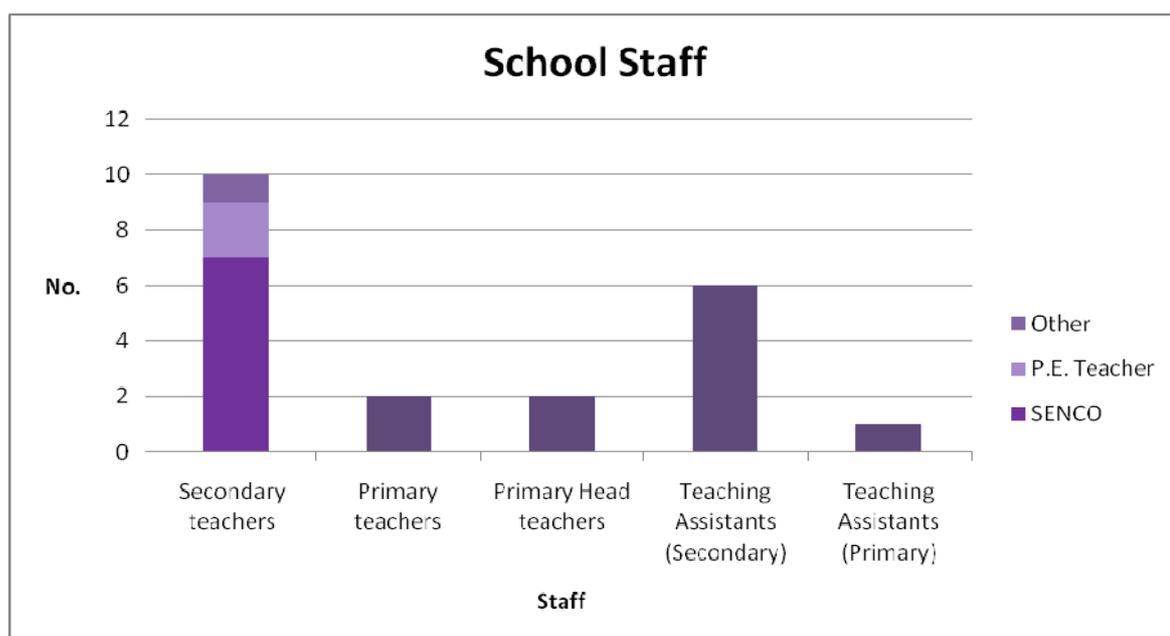
Recruitment of the sample

The children and young people who participated in the study were recruited from the database held by The Back-Up Trust. There are currently about 100 children and young people under the age of 18 on the database and initially 40 families were contacted about participated in the study. For ethical

considerations and because of the requirements of the Data Protection Act, the participants were contacted in the first instance by The Back-Up Trust, which then selected children and young people attending mainstream school.

The Back-Up Trust sent the children's parents or carers a letter, written by the researchers, which explained the study. The Trust followed this up by telephone to make sure the letter had been received, and to confirm that the parents and carers were willing for their details to be given to the researchers. A small number of families decided not to take part because of pressure of exams for the young person (n=2); some children were not attending mainstream school (n=2), some could not be reached by phone for consent to be confirmed (n=6) and a small number dropped out nearer the time of our visit (n=2). As a result, 29 young people and 28 of their parents and carers were included in the study, out of the 40 families who had been selected initially.

Once the research team was given the contact details of the families, they were phoned and visits to their homes and schools arranged. Some families (n= 4), gave consent for us to interview the young person and the parent, but did not give permission for us to interview any of the school staff. This was because they felt the relationship with the school was already strained and they did not wish for any further intervention. As a result, we did not visit all of the young person's schools. In a few cases, involving lengthy journeys, it was not possible to visit a young person's school for reasons of time. Consequently, a total of 23 school-based staff were interviewed in person; the other two professionals were interviewed on the telephone.

When we initially telephoned the family, the child or young person was given the choice of whether we visited them at home or at school. The vast majority of the young people chose for the research interview to take place in the home setting. Consequently, we often interviewed the young person and the parent/carer together, or certainly, at the same visit, and visited the young person's school to interview school staff on a separate occasion.

The research methods

Written notes were taken of all interviews and, with the participants' consent, the interviews were also audio-recorded to aid the writing up process and to ensure greater accuracy. Detailed summaries of the interviews were made, with verbatim quotations where appropriate, before analysis of the data took place.

Children and young people

We originally planned to visit the young people in their school setting so that they could show us around the school and take photos, where appropriate, of any physical barriers or helpful aspects of school life. Out of the 29 children included, we only visited 5 in the school setting, in accordance with the children's and parents' wishes. Some of the photos taken on these visits are referred to when we discuss the research findings and are included in the section on the physical environment.

Our interviews with children and young people took place in the presence of either a parent/carer or a member of the school staff, such as a teaching assistant. The interviews lasted between half an hour and an hour. We used a topic guide, which is included in the appendices, to ensure that broadly the same areas were covered in each interview. This topic guide included questions about what is was like for them to return to school after their injury (if appropriate); what they liked and disliked about school; examples of how they had been particularly included or excluded at school; who had been particularly helpful; what they wanted to do after leaving school, and any recommendations or messages they wanted to give to The Back-Up Trust.

Parents and carers

All parents and carers were interviewed in the home setting and the interviews tended to last between half an hour and an hour and a half. The parents and carers were given the choice of whether they were interviewed alone or with the child or young person. A small number chose to be interviewed alone, as they did not want to reveal, in front of the child, some of the difficulties they

had faced. Again we used a topic guide, which included topics and questions similar to those used with the young people. These included parents' perspective on the young person's return to school after the injury (where appropriate); how school was at the present time; what people or things at school helped or hindered the young person, and any recommendations they wanted to make about improving the school experiences of spinally injured children and young people.

Staff

Our interviews with school staff varied depending on who was available and the amount of time they could offer in the busy and structured school day. The interviews, as a result, lasted anything from 15 minutes to over an hour. For school staff, a slightly more structured interview schedule was used. This covered areas such as the opportunities and challenges facing the school when working with a child or young person with a spinal cord injury; details about any relevant training attended and the challenges in obtaining training; support and information they could access in relation to working with a spinally injured young person. The interview finished with the identification of the gaps they felt there were in resources, information, training and support. We finished the interview, as with the young people and their parents and carers, by asking for any recommendations they would give to help improve the quality of school experiences for young people with a SCI.

Ethical considerations

Before commencing the study, we applied for and received ethical approval from the Institute of Education's research ethics committee. We paid particular attention to informed consent and confidentiality of participants. As already explained, in order to comply with the requirements of both the Institute of Education's ethics committee and the Data Protection Act 1998, The Back-Up Trust made the initial contact with the participants to ensure that they were happy to be contacted by us. Young people and their families were given the choice of where we interviewed them and they were asked for their permission for us to contact their school. As part of the informed consent

procedure, all participants were given an information leaflet (see appendix) about the project and confidentiality and anonymity were assured. It was also made clear to participants that they were not obliged to answer any questions they were unhappy with and that they could withdraw from the study at any time without explanation. All participants were also told they would receive feedback in the form of a written summary of the research findings and recommendations. The children and young people who were interviewed each received a £10 gift voucher as a way of thanking them and valuing their contribution.

We have already explained that we adopted the social model of disability when designing and carrying out the study. For this reason we did not approach the study wanting to know about the child's injury, its causation or resulting symptoms or impairments. In addition, because of the traumatic nature of some of the young people's accidents or illnesses and subsequent injuries, we did not directly ask the family about the young person's level of injury or cause. Instead, we focused on collating data relating to the research questions – that is about the child's experiences of school.

All the names of the young people and staff interviewed have been changed to preserve their anonymity.

Research findings

Returning to school

Young people's experiences

Although a small number of the children who participated in the study had been spinally injured from birth or a very young age, the vast majority had obtained their injury later in childhood, spending several months or a year or more in hospital as a result. Consequently, they had to return to the school they had previously attended as an able-bodied student. Understandably, for many, this was a difficult and sometimes traumatic event. Malcolm, for example, returned to school just before his GCSEs, he said he felt *'uncomfortable'*, *'out of place'* and felt like *'everyone was watching him'*. Sidra described how she felt when she had to return to school after being injured:

> *"It was hard. I was scared. I didn't know what to expect. I didn't want to go back."* (Sidra, age 14).

A younger boy, Tim, also found the return to his primary school, after 4 months in hospital, an unsettling time and felt that people had changed:

> *"It was a bit weird. A lot of the class, I didn't even recognise them. Their personalities had changed and they were different"* (Tim, age 10).

For many, returning to school was a period of mixed emotions; it was enjoyable seeing friends again, while at the same time it was a difficult transition. As Alison, age 10, said:

> *"It was nice because I could see all my friends but also a bit weird because it was very different from hospital."*

Ian described how the positive side of seeing friends might also be accompanied by a feeling that he was returning to school in some ways as a *'different'* person:

> *"It was really good at first, although I was a bit shaken and a bit nervous at first about going in; I hadn't yet got used to how to handle my body and that"* (Ian, age 16).

Despite this, many of the young people pointed out that they did not wish to be treated any differently just because they had been spinally injured. A small number described people's attitudes towards them to have changed and said that they found this strange and, at times, patronising. Janine, for example, returned to school a wheelchair user, after 7 months in hospital. She described what it was like to go back to school:

> *"Strange and then happy. At first they treated me a bit differently but I said to them just treat me as normal. They kept asking 'do you need this, do you need that?' but I said, no, I can do it myself"*
> (Janine, age 17).

Ali described a similar experience when returning to Year 5 after being spinally injured:

> *"I remember the dinner lady – before she was always having a go at me and then when I came back in a wheelchair she was all sorry for me, which I don't want, some people are like that…..I don't want to be treated differently from other people"*
> (Ali, age 15)

Contact from teachers and friends

Some of the children appeared to be coping better when it came to returning to school. Many of these young people described how they had had visits from teachers and/or school friends while they were in hospital. These visits

were much appreciated by most and served as a bridge between their sudden and traumatic injury and their previous school life as an able-bodied person. Natalie, for example, explained that her Head of Year visited her while she was in hospital. She saw this visit as very important and helped her to *'maintain a link with the school'.* Janine was visited by her Head of Year and his wife, an event, which she described as *'nice'.* Although one boy, Ian, thought it was odd to see teachers outside school, many welcomed these visits and valued the continuity they provided.

Some young people also described receiving school work while they were in hospital or knew that a teacher from school was liasing with hospital teaching staff. One parent explained how her contact with the class teacher and the liaison between hospital staff and school staff had helped her son keep up-to-date with – or even ahead of – the curriculum.

Cards from the school, and sometimes from the whole class were also appreciated. One young girl, Alison, described how her class had continued calling out her name in the register and how some of her classmates pretended to answer questions for her in class. Gestures such as these served to show the children and young people that they were still being cared for by their school and not forgotten.

Others explained how having close friends – or the support from a teaching assistant, for example, to re-establish friendships – helped their return to school. David returned to school after 18 months in hospital and described what it was like:

> *"I was really shy to talk to everyone….but people encouraged me to make friends"* (David, age 13).

Preparing to return

Young people also coped better with the return to school when they had been properly prepared. Such preparations included a visit to school before

returning, sometimes with a parent or professional, such as an occupational therapist (OT). These meetings helped the young people re-establish contact with their friends and teachers and assess the physical accessibility of the school premises. Natalie explained that going back to school was daunting at first but visiting with an occupational therapist before her return to school had helped her in this transition. This visit showed her how she could get around and what was possible. She felt this was important and made it less daunting because she then '*knew in her mind'* what she could do.

Young people had also felt prepared by attending a meeting at the school with involved professionals and their parent or carer. Communication between the parents, young person and school seemed to be much more effective after the young person's return if such a meeting had occurred. These meetings were mainly organised by a hospital-based professional, such as a Resettlement Officer, Case Manager or sometimes an OT or physiotherapist. Parents we spoke to valued these meetings because it was a way of 'briefing' the school about their child's needs and assessing the physical environment. The young people who had attended these meetings had also seen as them valuable. One girl, Julie, had not been invited to the meeting, although she was 13 at the time of her return to school. As a result, she felt that she could have been listened to more and made the following recommendation:

> *"Ask the person in the wheelchair what they want to do and what they think about things instead of asking the parents all the time"*
> (Julie, age 18).

A small number of parents and carers, however, felt that there had not been enough communication with the school before their child's return. According to one mother, one child had returned to primary school and there had not been adequate communication with the whole school, including staff and children, about the child's situation. As this mother explained:

> *"It would have been useful to have someone go into the school beforehand to inform everyone…the parents and the children. The*

Head Teacher did the very basics but it did need more explanation than that…about the ins and outs of spinal cord injury….the basics" (Mother of Carly, age 10).

In contrast, one primary school Head Teacher spoke to all the children personally about wheelchair use and had read a '*Topsy and Tim'* book about a girl in a wheelchair to each class before Elizabeth started at the school. Although Elizabeth was starting at primary school rather than returning after being in hospital, the Head Teacher prepared the school for Elizabeth's arrival, and this was highly valued by her family, who saw this as very helpful for the transition to primary school. Another example of a primary school preparing the other children is given below.

Preparing a school for the return of a child with a SCI

The teachers and teaching assistants were anxious before David started at the school because he had a tracheotomy and used a ventilator. Health care professionals visited the school before David's admission to school and spoke to all school staff about what to expect. This reduced the anxiety levels among staff. The school then held assemblies about David's spinal injury and explained to the children about his ventilator and tracheotomy. They worked with the children about the issue of empathy and made them aware of David's time in hospital. The Head Teacher describes the school ethos as being one of social acceptance and the social model of disability:

"*The wheelchair and the fact that they can't move their legs is not their biggest problem….it's social acceptance and being seen as a person and not as a person in a wheelchair. If the whole school ethos is about meeting emotional and social needs then it doesn't matter so much about where your legs are".*
(Head Teacher, Primary School).

Many of the young people we spoke to were supposed to return gradually, doing half days at first, to ease them in gently. We found that when the young

people had been prepared in the ways described above, they rarely needed a long period of part-time hours and in fact were keen to return full-time almost immediately.

Delays in returning to school

For a few of the young people, there were delays in their return to school, because they had not received the support that they needed. Although Bob, for example, was desperate to return to school, he did not have the one-to-one support that he required at school. Fortunately for Bob, his mother was able to take on this role. However, because Bob mainly needed her assistance for bowel and bladder management, she spent much of her time at school as a volunteer helping others to read! Eventually the school recruited a Teaching Assistant for Bob, a process in which his mother was fully involved.

David's admission to school after his stay in hospital was also delayed. This was due to the lack of trained staff, particularly as David's spinal injury was severe and he needed health care input as well as general support. His Head Teacher explained the delays in getting people:

> *"We had to wait until everyone was trained before we could support David and had to use agency staff. The process of getting staff was very lengthy, like getting the job description and the person specification correct"* (Primary Head Teacher)

This Head Teacher went on to say that this type of information, such as a job description and person specification for a carer of a child with a spinal cord injury, could usefully be shared between schools, as it had taken them a great deal of time to develop. She made the recommendation that a generic job description, or at least a checklist of the things that need to be in place, before a child with a SCI is admitted to school would be helpful, in order to prevent everyone *'reinventing the wheel'.*

Moving schools

For a very small minority (n=3) of the children and young people we spoke to, returning to their original school was not a possible option. For two children this was as a result of accessibility issues. One young man, John, made the choice to move schools because, after a year in hospital, he was advised that he would need to join the year below him.

By definition, all the children and young people who participated in the study were in mainstream education. It is outside the remit of this study to comment on the experiences of children with a SCI in special education. Our interviews revealed that, for a very small number of children's families, a suggestion was made – either by a teacher, an education authority officer or the hospital – that they should consider special education for their son or daughter. The suggestion was usually made in the context of discussing adaptations that needed making in the original school. In these cases, parents and young people were shocked and outraged at such a suggestion. As this mother and daughter explained:

> *"I think it was about finding the quickest and cheapest way of dealing with this because it was so sudden and so unexpected. It was a knee jerk reaction maybe"*
> (Mother of Julie, age18)

> *"I would have said 'I'm not going' – end of story!"*
> (Julie, age 18, age 13 at time of injury).

Some children returned to schools where adaptations were still necessary despite them having been away for several months, and it being clear that they would be returning as wheelchair users. One boy, Ali, did return to his original primary school into Year 3, but after a while it became apparent the school premises were not in fact properly accessible for him. For example, his class was in a mobile classroom with steps leading into it. Also, there was no room inside to manoeuvre his wheelchair. He and his family were concerned

that many adaptations were necessary and that they would take too long. He was concerned about missing school while waiting for the changes to be carried out, and so made the difficult decision to change schools. Ali vividly described the emotional affect this had on him:

> "It wasn't very nice though; I missed friends, though I kept in touch with the close ones; it feels like you have lost a chunk of your heart and your friends and your childhood "
> (Ali, age 15).

Transferring from primary to secondary school

Many of the young people we spoke to were injured during their time at secondary school so transferring from primary to secondary schools was not an issue, although a small number had needed to transfer from secondary school to the 6th form. For those who had experienced the transition from primary to secondary school, a multi-agency meeting held near the end of Year 6 and attended by the young person, their family and education and health care professionals, was highly valued. The main education person to attend these meetings was normally the SENCO and often a teaching assistant.

One young person, Elizabeth, had showed everyone at the meeting how her catheter and callipers worked and, as her mother explained, this demonstration reassured a lot of the staff who were initially rather anxious about meeting Elizabeth's needs. The meeting was held at the secondary school in the summer term of Year 6 and was attended by the SENCO, teaching assistants, an occupational therapist and the family. Elizabeth's mother explained why such a meeting was beneficial:

> "*People get worried when they don't know and once you show them, they are not worried*" (Mother of Elizabeth age 14).

Another young person, Sarah, was injured while at primary school but had transferred to secondary school without a multi-agency meeting, like the one she had had when returning to primary school. Her mother compared the two different transitions:

> *"Had there been the same sort of meeting we had in primary with the OT and the physio and everyone, that would have been fantastic - definitely – because it was really helpful – and made her [Sarah] feel better as well"*
> (Mother of Sarah, age 14).

At the time of the study, Sarah was 14 and in Year 9. She was experiencing a range of difficulties at school, including some regarding access. For example, to access the art block, she had to go through every single classroom, to avoid a flight of steps. Unfortunately, the doors were usually locked, meaning that Sarah kept having to ask staff to unlock them. Sarah's mother said they had asked the school to put in a portable ramp, but wondered why these issues had not been addressed before Sarah transferred from primary school:

> *"What frustrates me is that they knew Sarah was coming; they knew her situation, well they must have done. When you put into going into a school, they knew she was statemented[1] and needed a ramp and everything. Why take a child on if you can't cater for her?"*
> (Mother of Sarah age 14).

One of the SENCOs we interviewed echoed this view when she explained how the local authority was delaying funding adaptations for the secondary school in which she worked. Referring to providing equipment to make the school more accessible, she said:

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[1] 'Statemented' refers to a statement of special educational needs. This is a written record resulting from an assessment carried out by the local authority. The statement sets out a child's needs at and the help they should have.

> *"It's about making mainstream education available. I said if this wasn't made available we weren't providing a mainstream education and they shouldn't send anymore disabled students to this school"*
> (SENCO, secondary school).

A primary school SENCO also spoke about the difficulties facing Paul in transferring to secondary school. She explained that although the Head of Year from the secondary school came to visit the primary school, no member of staff had visited Paul to see what his specific needs were. The day after Paul was seen for this research study, he was meant to go on a full day visit to his new school. He was only planning to attend for half a day instead of a full day because no one at the school had organised changing facilities for him.

Bob and his mother described in detail their visits to two possible schools when transferring to secondary education. The welcome they received and the attitudes that they encountered could not have been more contrasting, despite the schools being, academically, very similar and, geographically, very close. At the first secondary school, Bob's mother explained how the deputy head greeted her, asked whether she really thought that mainstream school was where Bob should be and said that there was not a lot they could do for him. During the open evening, only one other member of staff approached them and this was someone they already knew personally. This unwelcoming and negative impression stayed with Bob and his mother and was in complete contrast to a visit to the neighbouring secondary school. Bob's mother explained:

> *"They didn't see problems, just solutions. They said they would make sure he was accommodated"* (Mother of Bob, age 16).

Some young people and their parents felt that going to their local secondary school was out of the question, because of the adaptations necessary to make the building accessible. Alan's mother said she thought that, as a result of their experiences, it was necessary to start looking at secondary schools for

someone who used a wheelchair or with other mobility difficulties, as much as two years in advance of their requirement. Their local secondary school, which had been attended by Alan's older brothers, was on three floors and situated up a hill. Alan's mother reported that the local education authority said that if the school was adapted '*it would be vandalised in no time'.* Consequently, the family looked around at other, more accessible schools, one of which Alan started to attend. However, because this was not his most local school he initially felt isolated:

> *"It was scary, I wasn't confident. I was self-conscious about what they thought of me, but they accepted me"* (Alan, age 17).

Similarly, when Mary came to apply to secondary schools, many local schools said they could not take her due to a lack of suitable toilet facilities. Because Mary was refused places at her local schools, the family asked the local authority's special educational needs and psychology service for their advice and support. Following their intervention, Mary was offered a place, within a week, from one of the local schools that had originally refused her. Although a multi-agency meeting at the school was set up before the transition, which Mary's mother had found very beneficial, Mary was now experiencing a number of difficulties at the school, such as missing out on school trips and being excluded from PE.

The fact that Mary was initially refused a place at the school, which she eventually attended, appears to indicate that the school did not have an attitude towards disabled children conducive to her inclusion in school activities. As Bob's family concluded, if the school does not appear to be positive towards disabled children from the outset, it is unlikely that the school will be able to meet the child's needs and fully include him or her. Although, the *Disability Discrimination Act 2005*, requires schools to include disabled children, as some parents explained, they do not wish to try and impose legislative requirements on a school if the attitude towards them is negative from the outset. As Adrian's mother commented:

> *"In one meeting, we muttered about the DDA and they were very, very defensive. We've never gone down that path because if the school don't want him [Adrian], then we don't want the school. We don't want to make Adrian the trailblazer and for us to make it uncomfortable for him by insisting on his rights"*
>
> (Mother of Adrian, age 10).

More discussion of the attitudes of schools towards disabled children encountered by the parents and young people, and vice versa, in addition to an examination of the physical environment and adaptations, is given in further sections of this report.

The physical environment

Almost all the children and young people who participated in the study had experienced problems, to some degree, accessing the school's physical environment. This was even the case for the young people who were very positive about their school lives. The most common difficulties encountered were very heavy doors, ramps that were too steep and classrooms that were impossible or difficult to access, as a result of steps. Many young people complained to us about the weight of the doors at school and questioned why automatic doors were rarely installed. They thought this was likely to be as a result of funding restrictions but also because of health and safety rules, in that the heavy doors were fire doors. These heavy doors, however, had a direct effect on the young people's level of independence. As Alan observed:

> *"You're denying the disabled person their freedom because they don't want other people to open and close doors for them*" (Alan, age 17).

As a result, we found no correlation between the severity of the spinal cord injury and the young person's ability to get around the school. In accordance with the social model of disability we can conclude that the school environment – heavy doors being one example - disables the young person more than the injury itself. John was another example of this. He is tetraplegic

but reported no difficulties at school in accessing the school's physical environment. He described the school setting:

> *"The buildings are 1960s, but easy to get around. The doors are fine. Some are automatic and I generally fit through all the doors"*
> (John, age 18).

Similarly, David, who is also tetraplegic and used a ventilator, and therefore, more severely impaired than most of the young people in our sample, found his school building very accessible. Whilst showing the researcher around school, he particularly pointed out a large ramp with easy access to the playground, and commented:

> *"The ramps are very helpful; if we didn't have all the ramps, it would be really difficult for me to get in and out"*
> (David, age 13).

David also liked the fact that the classrooms were big enough for his large wheelchair. A more common finding was the lack of classroom space for young people to manoeuvre their wheelchair or to use other equipment, such as a standing frame.

For most young people, there was at least one room or area in the school that they could not access. Neither Natalie, nor Ali nor Alison, for example, could access the library, as it was upstairs. In addition, Elizabeth had to go down several corridors to access her language block, a journey that took her much longer than everyone else. Sanya could not access her Information Technology (IT) room, which was upstairs and as a result, she had to do IT downstairs away from the rest of her class. The school had made attempts to compensate her for this exclusion by allowing two of her friends, in addition to the teaching assistant, to work downstairs with her.

When Sarah first returned to school, her classroom was upstairs. Rather than miss school, her mother would take her into school and carry her upstairs in

the morning, and bring her back down at the end of the school day. Although there was a common room upstairs for her year (Year 6), which she could use during the day, Sarah could not go outside at all.

Some young people described their classes being moved so that they could be on the ground floor and new ramps being installed to make the building more accessible. The young people who experienced the fewest problems in accessibility were in schools with a history of having children with mobility difficulties, so that the building had already been adapted. The availability of funding for adaptations and the attitude towards disability of both the school and the local authority also had a huge impact on the extent to which how much the building was adapted and how quickly this was completed. One secondary school SENCO we spoke to said that there had been difficulties obtaining funding for adaptations when another wheelchair user had been at the school. This was because he had come from another secondary school, which had already been given a lot of funding to make it more accessible. Another secondary school SENCO said that the school had full support from the local authority Access Team:

> *"Requests have been made and we've never been turned down"* (SENCO, secondary school).

This school received 100% funding for changing a shed into a physiotherapy room and for 50% funding for their evacuee chairs, to use on the stairs, in case of fire, finding the other 50% from the school budget. Both SENCOs expressed the view that the process of adapting the school was an *'on-going, organic one':*

> *"These changes have been part of our accessibility plan – in response to the DDA. We can't do everything at once as it all takes careful planning"* (SENCO, secondary school).

Special Units

Although all the schools that the children in our study attended were mainstream schools, some of them – both primary and secondary – had special units for children and young people with disabilities, which included children with emotional and behavioural difficulties. None of the children interviewed were educated in these special units but some of them started and/or finished the day there, or were able to go to the unit for 'quiet' time, to rest or do homework. Only a small number of our sample (n=4) spoke about experiencing these units but all but one were positive about them. John described the benefits of having a separate area that he could use:

> *"They have a whole section for people with disabilities, not just with wheelchairs. It's a quiet area, all the teaching assistants are there and no other kids walk through it and you can work there."*
> (John, age 18).

For a primary school boy, David, his teacher described the separate area as a *'safe haven'*, and according to Ian's mother, it was a *'sanctuary'* when Ian was feeling rather overwhelmed or just wanted to catch up on homework. Alan also appreciated being able to go to a separate area at break times when he first started school in Year 7 as he said he lacked confidence at this time.

Special equipment

Many of the young people had been provided with specialist equipment from the occupational therapist or physiotherapist, such as a special chair that moved up and down, or an adjustable table or workstation, such as a 'high-low' table. There were mixed views about the value of these pieces of specialist equipment. Some young people felt that having 'special' equipment singled them out and was actually unnecessary. Bob, for instance, did not want a special chair as he felt it restricted him. Likewise, Julie was given a 'high-low' table but felt she did not need it and said that it dictated where she sat:

"The tables were fine! It irritated me because they didn't need to change it. I didn't even need a high-low table – they were making a big fanfare over something that was fine, that didn't need to be changed. They gave me a high-low table for science though there was a table that was fine for me; it meant I was restricted where I sat every lesson. I had to sit at the front which was annoying" (Julie, age 18).

In contrast, Elizabeth was full of praise for the adjustable work-station that she had access to in her food technology rooms and Vivien, who did not have such a work-station, complained that she was not able to reach the surface in her food technology lessons. Sarah was identified as needing a soft-backed chair but this was not made available to her; one teacher told her to '*bring a cushion from home'.*

Physiotherapy rooms
Some schools had installed a room solely for physiotherapy use, which meant that young people did not have to leave the school site for their physiotherapy. However, some young people complained that they had to miss either lessons or lunchtimes in order to have physiotherapy. Mary and her mother reported that she had never had a geography lesson while at secondary school, because she was always having physiotherapy at that time. Now she had dropped geography she was missing art, one of her favourite subjects. Julie managed to re-arrange her physiotherapy to periods outside school:

"I had to do it [physiotherapy] at lunchtimes but I missed my friends. I didn't want to miss my lessons. I started to have physio outside – it wasn't practical at school at all" (Julie age 18).

Toilets
The lack of adequate disabled accessible toilets was mentioned by many of the young people we interviewed for the study. Ian's return to school was delayed by the lack of adequate toilet facilities and Julie described the disabled toilet at her school a *'token gesture':*

> "*It's just a bigger toilet – there's nothing else that would make it disabled*" (Julie, age 18).

Additionally, Alan said that although the toilet was supposed to be a 'disabled' one, it was not the right size and there was a huge sink under the dryer, which was too near the toilet. The disabled toilet Janine had to use was also inadequate for her requirements, meaning that she had to go to the special school, situated next door, when she needed to use the toilet:

> *"The toilet is a square shape and you can't get your chair around near the toilet – it's real hard. There's not much space to move around so I have to go to the [special] school next door to use the toilet and get changed"*
> (Janine, age 16).

Some of the young people said that the disabled toilet was free for anyone in the school to use, meaning that the toilet was frequently in use when they needed it. One boy, Billy, said the disabled toilet in his school was used for storing other students' bags and it was easy for other students to open the door by using a coin in the lock. This meant that when he used the toilet, he was constantly anxious that someone would come in to get his or her bag, with the result that he felt he had to rush. Felicity's school also allowed anyone to use the disabled toilet, and as she said:

> *"There's only one disabled toilet, which is a bit of a pain particularly as others use it. Sometimes I get a bit desperate. I go to the normal toilet but the doors are a bit small so I ram myself through"*
> (Felicity, age 14).

In contrast, in Elizabeth's secondary school, the disabled toilet was only for the use of disabled students or staff and she held a radar key for this. Consequently, she reported no difficulties in accessing the toilet when she needed to use it:

"I have a disabled toilet which I use; it's really good. No one else uses it" (Elizabeth, age 14).

Parking

A small number of parents we spoke to identified the lack of disabled parking spaces at school as a problem for them. Some also said that other non-disabled people were using the spaces and that the school needed to do more to monitor their use. Carly's mother, for example, told us that for the last 18 months she was not allowed to park on the school drive because, she was told, of the health and safety of the other children. As a result she had to bring Carly 15 minutes later than everyone else, which, she said, made them both '*feel uncomfortable ….and makes Carly feel different'*.

Friendships

We have already said that many of the young people welcomed returning to school after hospitalisation so that they could see their friends again, but that their relationship with them had sometimes changed. As Ian explained:

"My best friend has been great, hasn't changed towards us at all. They [other young people] were a bit cautious at first but then got used to it. People at high school were a bit hesitant at first but my close friends understand. I had a knock in confidence so it was hard at first to make friends" (Ian, age 16).

Ian went on to recommend that the peer group of children and young people with a SCI should be given information about the condition, what it meant and how they could help, in a similar way that David's school was prepared for his admission (see page 22). As Ian explained*:*

"They want to help but they are reluctant – they don't know what to do or say" (Ian age 16).

Several of the older young people referred to their initial lack of confidence when they were first injured and how this had affected their friendships. Many of these said that it was only through greater experience and self-acceptance that their friendships improved:

> *"The other kids won't accept you until you show you've accepted yourself"* (Alan, age 17).

John, age 18, was very positive about his peer relationships and friendships at school:

> *"Because I'm only there in twilight hours now, I only see people of my age, and they're not exactly stupid – they know how to talk to me"* (John, age 18).

Furthermore, one teaching assistant described the positive impact on the behaviour of the other young people in Janine's school:

> *"It [the SCI] makes them more aware. There's a positive impact – they are so genuinely nice to her, like the boys hold the door open for her and actually come back and do it"* (Teaching Assistant, secondary school).

Generally, it was primary and younger secondary school children who had the most difficulties at school, in regard to peer relationships and friendships. Billy, for example, explained how his friends would sometimes carry his bags but not all the time, making it very awkward for him to ask:

> *"Some of them help for say two weeks and then say 'ask someone else'. There should be a rota or bag monitor or something"* (Billy, age 13).

Tim, age 10, and in Year 6 at primary school, felt that he was teased at times, which made him very sad. In the following quotation, Tim appears to be blaming himself for the behaviour of the others in the classroom:

> *"Sometimes when I'm in a bad mood and they want to get at me, then they call me 'disabled'. Sometimes when I'm in a bad mood they're like 'be careful' and stuff. And then I might turn around and they'd say 'sorry, oh it's your back isn't it?"* (Tim, age 10).

Paul, also in Year 6, described some difficulties in his peer relationships at school and at times said he felt blamed for things:

> *"When they get on me nerves, I just argue back. The whole of them. Drives me nuts. They tell me off and not the person who did it"* (Paul, age 11).

His teacher confirmed some of these problems:

> *"It's been a long hard battle for Paul to make friends. Children don't really understand what it entails for Paul. They wouldn't let him play, saying he couldn't do it. But he has his hands, if not his legs"* (Teacher, primary school).

Paul's situation is strikingly different to David's, a boy of the same age and with a more severe degree of SCI. On page 22 of this report, we described how the school had been prepared for his admission. David, when interviewed, said, *"I find it easy to make friends"*. Interestingly, Paul's teacher had suggested to the school that disability and Paul's spinal injury should be discussed in Personal Health and Social Education (PHSE) lessons, but this suggestion had not been taken up. Based on these two contrasting examples, the ethos and how it prepares for a disabled child are far more important factors in determining a child's peer relationships in school, than the injury itself.

Similarly, Alison, age 10, and in Year 5 at primary school, described how her friends helped her at school:

> *"My friends like to help out. If I can't open something, they help me; I ask them and they say 'yes'. That makes me feel quite happy as it makes me feel like there are lots of nice people around to help"* (Alison, age 10).

Again, Alison's mother, told us that the school had had a 'Disability Awareness' programme, where disabled people came into the school and spoke to the children about disability and some of the challenges they encounter. This mother said the school also has an 'inclusion assembly' at which the children are made more aware of disability and its implications.

Sarah, age 14, described feeling isolated at school because a lot of the girls saw each other outside school but she did not; also that they would talk about boyfriends a lot at school and she could not participate. Her mother wondered whether having a teaching assistant with Sarah was inhibiting her friendships and preventing other girls from bringing Sarah into the conversation. More about the role of the teaching assistant and the impact on social relationships will be presented in a further section of the report. Being restricted at lunch times also had an impact on her peer relationships; this was a common finding that will be discussed later in the report.

Pushing the wheelchair

Some of the children had experienced problems in the school's policy towards other children and young people pushing their wheelchairs. Some schools had banned this altogether, while in others it was accepted that being pushed was part of the wheelchair user's school experience as well as the experience of the able-bodied peers of a friend using a wheelchair. Ali explained that his friends were not allowed to push him in his wheelchair, for health and safety reasons, but that sometimes this rule was broken:

"My friends aren't allowed to push me because of health and safety in case something went wrong of I fell out of my chair or whatever, because the school would be responsible. Occasionally we bend it – sometimes the children do push me – I'm not going down Mount Everest or anything!" (Ali, age 15).

Several of the mothers interviewed expressed quite strong views in support of their sons or daughters being pushed by other children. For Sarah, her problems with friendships began, according to her mother, when in Year 8 a member of staff banned any other children from pushing the wheelchair. Because there was no teaching assistant available at lunchtime to take Sarah out in the playground, she was not able to go out and as a result, stopped interacting with her peers. Elizabeth's mother likened pushing the wheelchair to being affectionate with your friends:

*"Elizabeth is sometimes pushed around by her friends – if she doesn't like it, she'll tell them. Pushing someone around is a bit like putting your arm around someone; I think it's affectionate; it's like they are just walking off with her" (*Mother of Elizabeth age 14).

Other mothers said that their children would be fine if they fell out of their wheelchair anyway; they likened this to any child falling over. Clearly, this is not the case for all young people who are spinally injured, but it appears that schools need to base a decision about children pushing their friends' wheelchair on individual circumstances, rather than making it a 'blanket ban'.

Lunchtime

In terms of feeling isolated or excluded, lunchtime was a key time for many of the young people who participated in the study. The vast majority we spoke to had been advised to leave lessons five minutes early to avoid the 'crush' of the lunch period. Although the schools had the best of intentions in requiring this, this practice caused many of the young people to feel isolated at what should be the most sociable time of the school day.

Ian's dining area, for example, was hard to access because there were too many tables and he *'couldn't fit through'* so he ended up having to get there earlier than everyone else. He described the experience as a lonely one:

> *"It was like being excluded really because I was allowed to go 5 or 10 minutes early so I'd end up sitting by myself in this empty dinner hall eating lunch"* (Ian, age 16).

Ali also explained how the practice of leaving lessons early made him feel singled out and affected his academic work:

> *"There's an expectation that you should go first because you're in a wheelchair but I don't want to be given major priority. I don't want to be treated differently. Missing the last few minutes is also difficult because the teacher is often setting home work"* (Ali, age 15).

Both boys found their own solutions to these unsatisfactory situations. Ian told us that he and many of his friends started to '*buy stuff and stand outside',* which he was much happier with. Ali had begun to stay in the classroom until after the others had left, or to '*find another route'* to the dining room, meaning that he did not need to leave lessons earlier than his peers did.

A small number of children could not access the dining area at all because the school did not see it as 'safe' or because it was completely inaccessible to a wheelchair user. Paul, for instance, could not reach the upper hall in his primary school, where the children had their lunch. For three years, he ate in his classroom downstairs, although he was always put with some other children, so he was not on his own. Sarah's sister reported that Sarah was not allowed in the canteen because of the crowds, so Sarah had to sit in the Learning Support Unit on her own and could have only sandwiches, rather than the choice of a hot meal. Sarah herself painted a vivid picture of the resulting isolation:

> *"I used to dread lunch. I felt like a prisoner. I used to worry about it the day before"* (Sarah, age 14).

Felicity reported having to wait outside the dinner hall while her teaching assistant would carry her tray and go in and order her meal. Felicity did not like the fact that she did not see her food before it was ordered. After raising this issue with the SENCO, it was agreed that one of Felicity's friends could carry her tray while Felicity manoeuvred herself around the dining area.

PE and sport

When it came to doing PE and sport at school, our sample of children and young people seemed to fall into one of two distinct camps. One group, which was about a third of the sample, appeared to be fully included in all aspects of PE and the other group, about two-thirds of the sample, had experienced problems with PE at school and had either felt they were sidelined or excluded from PE altogether. Many of the young people who were having a good experience of PE at school were studying either GCSE or 'A' level PE and some were participating in sport at a national level and aiming to take part in the 2012 Paralympics.

Many of the children, with a more negative experience of PE, reported finding grass sports pitches very difficult to access, especially when it was muddy. Some young people reported only participating as an umpire; although this was valued by the young people, they did not want to be doing it all the time and felt that more effort should be made to adapt the activities for them.

Bob, for example, was told he was a 'hazard' when playing rugby and the teachers tried to make him do something else. He understandably did not want to be segregated from the rest of the class. Billy, who could walk a little, also described experiences of segregation and stigmatisation when it came to sports day at school:

> *"I hated Sports Day. It's supposed to be fun but I hated it. It was more demoralising than helpful, like doing the 100 metres and being at the end 20 seconds after everyone else".* (Billy age 13).

For the next Sports Day, the school decided to put all the disabled children in one race, which exacerbated this stigmatising experience:

> *"It was like a freak race, all the children in wheelchairs in one race!"* (Billy, age 13).

Alison, too, felt very isolated during some PE lessons because the activities were not adapted for her:

> *"When they do apparatus, I can't do that so I feel left out so I do some walking. I remember one time I had to go in my standing frame, and they were doing apparatus, so instead of watching them do PE I had to do school work and felt like I'd been naughty*" (Alison, age 10).

Sarah, despite attending a specialist sports secondary school, was being completely excluded from PE:

> *"I don't do PE! When they do PE, I go to the library!"* (Sarah, age 14).

Other young people, in contrast, such as Ali, David, Julie and Elizabeth, all felt fully included in all the different PE activities and when this was difficult or impossible, an activity was adapted for them:

> *"My PE teacher made me do everything – they adapted everything. I'm not into sport – I didn't have a choice! My teacher adapted it all so I had to take part. She was quite strict so she didn't want me sitting on the side and not taking part*" (Julie, age 18).

David, despite having a severe level of spinal injury, also felt very included:

> *"In PE if they were doing stretches, they would stretch my arms……and on the field we do team games like rounders and relay racing……and cricket. I use a tennis racket because it's easy to use – that helps"* (David, age 12).

Elizabeth, age 14, who was very keen on PE and sport, had a similar experience, and felt she benefited from the PE staff's support and enthusiasm. Her school experience of PE and that of her mother is given below.

Positive experience of PE and sport at school

Elizabeth, age 14, was keen on PE and, at first, was anxious that she would not be able to take part in PE. However, as she explained:

> *"The PE department is really up for everything. We talked about how I love sport and they were up for everything; they worked everything out"* (Elizabeth, age 14).

For example, the PE teachers had developed a pentathlon specifically for Elizabeth. This consisted of three throwing events, three running events and one obstacle. She was timed in all these activities each week, to ensure that she was challenging her personal best results. She also took part in the cross-country race. Because Elizabeth found it very difficult to wheel herself on grass, the PE teachers adapted the route for her so she could go on the street. She did the same distance as the others and was timed the same way as the other young people.

The school purchased and used specialist equipment, such as boccia balls and special bats. They also organised a demonstration of wheelchair basketball so that the able-bodied young people could experience basketball in a wheelchair.

Elizabeth's mother also worked in close partnership with the school in order to adapt PE for her. As she explained:

> "For one race, they were going to push her but I said that was no good, she hasn't achieved anything; it was far better for her to start a bit further forward. She pushed herself so at least she was doing it herself and it was a bit more on an equal footing. They were OK and took everything on board; they maybe hadn't thought about it but that's not their fault; they always ask my advice about things"
> (Mother of Elizabeth, age 14).

A few of the young people, like Simon and Natalie, said that they felt it was their responsibility to let the PE staff know what they could and could not do when it came to PE:

> "I think PE staff need to be definitely more inclusive. They need to be quite encouraging to do things but also let you decide what you can do by yourself" (Natalie, age 17).

Swimming

Several children and their parents mentioned difficulties in going swimming with the school, either because of the lack of suitable changing facilities or of a hoist to aid the young person entering the pool. One young person could not attend because the coach the school used for transport was not accessible, and some children complained about the temperature of the pool being too cold for them.

PE teaching

Although sport was very important for Alan, and he very much wanted to do a GCSE in PE, he was told that the course could not be adapted for him. He was very disappointed, especially when the following year he was told that it could have been adapted after all. He concluded that the teaching of PE at his secondary school was *'rubbish'* and that they '*had no experience at teaching*

disabled people'. Billy, similarly, was critical of the standard of PE teaching in his school commenting:

> *"They don't really know what to do with a disabled person – their curriculum doesn't really fit around it"* (Billy, age 13).

Many school staff we spoke to had managed to obtain specialist equipment to adapt PE lessons. This included lower netball nets, a lower table tennis table, balloon balls, larger tennis rackets or those adapted with a special strap and bean bags. One school had also purchased boccia balls, a game similar to bowls, specifically designed for physically disabled people. Funding restrictions, however, were cited as a challenge in obtaining such equipment, especially as there may be only one or two disabled children in a mainstream school.

A small number of teachers had attended a specialist course about teaching PE for disabled children but it was felt that these courses were more geared to teachers in special schools. They would have welcomed more advice:

> *"Really we need more help and ideas about PE for children in wheelchairs. I had some training from a teacher from a special school but that's a bit different and we have to adapt it all. It's not really geared towards having one or two children who are disabled. So we need more guidance on how to adapt things alongside more able-bodied children"* (Head of PE, secondary school).

Natalie's mother echoed this view, that most – if not all – PE teachers in mainstream school need more guidance on how to adapt PE for wheelchair users:

> *"The sports teacher was lovely and tried to include Natalie but he didn't have any experience of her needs. How lovely it would have been if the school had brought in someone who could have advised them on how to include a wheelchair user in their regular lessons, or brought*

someone in who could have taken Natalie on one side and teach her
wheelchair basketball. That would have been great"
(Mother of Natalie, age 17).

Transport and school trips

Transport to and from school

A very common experience for most of the young people and their families
were problems in using the local authority transport service to and from
school, a service which was, in most cases, contracted out to a private
company. For many young people, the taxi or mini-bus that collected them
arrived very early in the morning meaning that they were travelling for about
an hour to get to school, picking up others on a long route, although they lived
only a few minutes away. For many, this experience was repeated in the
afternoon, making the day a very long one. Worse, though, was experiencing
unreliable transport, with taxis not turning up to collect the young person at
the correct time, so that some young people were receiving 'late marks' at no
fault of their own. One young person, Julie, reported a taxi making her late for
an exam. When she and her mother complained, they said they were accused
of lying by the transport company:

> *"Transport – at the moment it's horrendous! They come when they're*
> *not supposed to come and not come when they are supposed to. They*
> *made me late for an exam. They say we are lying! Anything out of the*
> *ordinary they can't cope with."* (Julie, age 18).

The lack of flexibility of school transport was identified as a problem by
several young people and their parents, and had implications for the young
people's ability to attend after school clubs and see friends after school. As Ali
explained:

> *"I have found leaving late after school a problem; it is not in their contract. My sister has to collect me"* (Ali, age 15).

And for Billy, like many, the lack of flexibility had had a negative impact on his social life after school. As his mother commented:

> *"You should have a rule with transport that when you want a friend home for tea you can. I know it's difficult but you really need the flexibility of transport"* (Mother of Billy, age 13).

Mary was not able to do wheelchair basketball after school because of the inflexibility of transport arrangements. As her mother said:

> *"Transport collects her and brings her home, but she misses basketball because it's after school and the transport isn't flexible – they need to relax their rules" (*Mother of Mary, age 15).

In fact, one or two of the young people did experience more adaptable transport, due to the fact that they almost always had the same driver who had got to know the young person and the family quite well. Being familiar with the young person and his or her friends meant they could 'bend' the rules a little. Elizabeth's mother explained:

> *"Sometimes he [the driver] brings her friends home with her too, which I'm sure he's not supposed to do. Another time, he dropped her in town as she needed to go to a confirmation class. It's about give and take – sometimes we do it if a problem with shifts occurs"*
> (Mother of Elizabeth, age 14).

Janine also reported that her transport was reliable and flexible; she told us that all she needed to do was to phone or text the driver and he would collect her.

School trips

The vast majority of the young people and parents interviewed identified school trips as one of the most problematic areas of their mainstream school experience. The main reason for this was the lack of disability accessible transport. Many reported their local authorities as not having any such coaches, or only making them available very recently. Some said they were available but the school was not prepared to use them because of the additional cost, which they would have to pass onto the other students. As a result, many of the young people we spoke to had to travel separately from the majority of their school friends on school trips, having to travel behind the coach in a taxi. Most schools attempted to compensate the young people by allowing one or two friends to travel with them, but for many, this was still an isolating experience.

Ali described his experience of being separated from the rest of his class:

> *"With secondary school, I have to go in a black cab – it's not nice because you feel isolated, kind of thing. The others go in a school mini-bus, which isn't accessible. Black cabs aren't the most spacious of cars and I have to have a teaching assistant with me and sometimes I have a friend, but it's not the same, it's not being included in the whole group"*
> (Ali, age 15).

Although Vivien's school had booked a disabled accessible coach for the school trip to see 'Billy Elliott', when the coach arrived, the aisle was not big enough for her to transfer into a seat. Vivien's father ended up driving her to London in his car behind the school coach, which was not ideal, given that it was a social occasion.

Mary, age 15 at the time of the study, had been particularly excluded from school trips. During her time in primary school, she could only go on a trip if she went in her mother's car. As she explained:

"I'd have preferred to have gone with everyone else from school" (Mary, age 15).

At secondary school, she did not go to any school trips at all, because, she said, the staff *'would have to carry me'.* To be excluded altogether was a rare experience but many young people experienced difficulties other than unsuitable transport. Ian described one of his school trips as a *'disaster':*

"The trip to Hadrian's Wall – that was a bit of a disaster! Lots of hills, lots of places I couldn't go; the gift shop was up a flight of stairs" (Ian, age 16).

One secondary school SENCO spoke at length about the need for careful forward planning when organising school trips that included a disabled young person. In this school, both the young person (Elizabeth) and her mother were full of praise for always including Elizabeth in school trips. The SENCO explained why she thought they had got it 'right':

"It's about staff being aware. It's about the hierarchy making sure that when anyone's organising a school trip, that on the paperwork it says, is there disabled access, and they check it with the centre. It's about making sure they've got accessible transport because it's more expensive, and about accessing the school budget set aside for doing that; that's what I have to enforce and check on."
(SENCO, secondary school).

The role of the Teaching Assistant

The role of the SENCO was identified by many young people and their parents as the first port of call if issues needed to be raised, and for co-ordinating meetings at school. However, the young people discussed the role of the teaching assistant (TA) in great detail, so it is this topic to which we now turn. For many children and young people, the relationship they had with the

TA was central to their experiences at school and often determined both how they felt about school, and their levels of independence.

Some of the young people had one TA allocated to them full-time, some had several TAs helping them at different times of the day, and some shared TAs with other young people. This variety of experience did not appear to be related to the severity of disability but instead to the assessment of need made in the young person's statement of special educational needs, and how this was translated into available funding by the local authority and school.

Because the TA had transferred with them, several of the young people had had the same TA throughout primary and secondary school. Generally this was seen as very positive ensuring continuity in what could be a very personal relationship, especially as many of the TAs were helping the young people with their bowel and bladder management. However, some young people highlighted the need for TAs to strike the difficult balance of being caring without being overbearing or over-protective. As this primary Head Teacher explained:

> *"The TAs come into the job because they are caring people, but the danger comes that with being caring becomes very protective. It's making sure that the support level is exactly that…....that it's support and not limiting"* (Head Teacher, junior school).

In fact, many of the young people told that this was indeed a problem and that the TA or TAs allocated to them were at times overprotective or dominant. Ian, for example, felt that the TAs were *'over helping'*, sometimes *'condescending'* and pushing his wheelchair without asking him first. He went onto explain how his relationship with the TA was very unclear at first and that he needed to learn how to be 'disabled':

> *"At that point I was still very ignorant about everything. They didn't know what to do and I didn't know what to do; I didn't know how to tell them and they didn't know how to ask"* (Ian, age 16).

Ali spoke to us at length about the difficulty of having a TA and the impact on his freedom and independence:

> *"Science has caused me a few problems. In terms of practicals, I need TAs with me [for health and safety reasons] which I've not been comfortable with – you want your freedom. The TAs ask me 'is there anything you need? Are you OK? And I wanted to shout at them, 'I'm not mentally disabled you know, I'm physically disabled; if I want anything, I'll tell you!"*
> (Ali age 15).

Some of the older young people described the problem of boundaries, when the TA tried to become friends with them:

> *"Some try to become your friends with you which isn't what I want, especially when they're 60 or whatever!"* (Ian, age 16).

Some parents were concerned that having a TA all the time was restricting the young person's social development, as they were not able to spend time with their friends alone.

Julie felt very strongly that the TAs should have strict boundaries:

> *"I didn't think I needed them really! I didn't want them. It's just not normal having some woman I don't know hanging around with me. I thought it was weird. I would say although they have to be there, they should be in the background and not try to be part of my group of friends"*
> (Julie, age 18).

Some young people felt that their TA had got the 'balance right' and had the experience to know when to leave them alone, either in lessons or when they were with their friends. David, for example, explained that although he needed

his TA at first because he was 'shy to make friends', they now know when to separate:

> *"Now I leave Ellie [TA] behind me and I run off with my friends. Ellie will be one side of the playground from me"* (David, age 12).

Ali explained how, by his talking to key people at school and in his review meetings, the TAs had learnt to 'back off' a bit and give him more freedom. For example, Ali was no longer having a TA with him in science lessons. Although the TAs were always on the same floor as him, in case they were needed (in a fire alarm, for example), they were no longer required to be in the same classroom. He explained that this had been a gradual, but welcome, process.

A couple of the boys mentioned the need for more male TAs.

> *"I've had older and young TAs- it's better if they're younger – they're more fun – and it's better to have one of the same sex. This year all my TAs have been male and that's been good"* (Simon, age 16).

Many of the children and young people and their parents were full of praise for their TA, very positive about the TAs approach and about their relationship with them. For many, this was about getting the correct balance: caring for the young person, while at the same time not becoming over-involved, sentimental, or trying to cross the boundary into friendship. Adrian's parents, for example, praised the TA's ability to minimise any fuss if Adrian had an 'accident' (that is, if he wet or soiled himself), and for being matter of fact about everything. As this mother explained:

> *"She's engaged but not over-engaged, doesn't say, aaaarh, oh dear; she's just very helpful but doesn't mollycoddle him. That would be the danger, he wouldn't have liked that, she's very matter of fact"*
> (Mother of Adrian, age 10).

Often the success of a TA - child relationship was about the child feeling genuinely liked and cared for:

> *"She [the TA] was a really nice person and she cared, rather than doing it because she was being paid for like bog standard, she actually went the extra mile. For instance, like little stuff, she brought me little presents for birthday and Christmas and I could talk to her about normal stuff, we were really open"*
> (Ben, age 13).

One secondary school teacher spoke strongly about the importance of the TAs role and how it was crucial to get it 'right':

> *"The TAs who have worked with Anna have been superb…..and I think that's important and something that we need to get right. Having the right TA is absolutely essential. Without that it would be very very difficult"*
> (Teacher, secondary school).

Training

All but one of the teaching assistants we interviewed for the study had attended a one-day manual-handling and lifting course run by the local authority. A small number of TAs mentioned doing short refresher courses too or a short course on using a hoist and a catheter. The only other training mentioned was informal on-site training with the young person's physiotherapist, for example. Most TAs did not feel the need for more training, although one said she would have liked more information about SCIs:

> *"It would have been useful to have more information about the condition [SCI] itself and what happens"*
> (Teaching Assistant, secondary school).

Simon's mother felt strongly about the need for TAs to have more formal training for working with a child with a SCI:

"Training can be an issue. The physio goes in to show one of the helpers what to do in terms of getting Simon into his walking frame. But there are a number of helpers and one helper then shows the other helpers, which is not ideal. Simon ended up with a pressure sore because it was done incorrectly. These TAs would benefit from a better understanding of the issues around SCI"
(Mother of Simon, age 15)

Another mother had actually organised and paid for a training course for the TAs herself because she felt so strongly about their need for training. She felt that the TAs only saw their role in terms of manual handling and did not understand the *'barriers of SCI'*. She wanted the training to show them that their job was not '*just about catheters and bowels'*. She was providing an understanding that disability is complex, involving the whole person, not only his or her body.

One secondary school teacher we spoke to also identified the need for TAs to receive more training, especially as their role is so broad ranging, not just about practical tasks but also about both feelings and the student's learning process:

"The people who could benefit from more training are the TAs who work with them [children with SCI]. I wonder whether it would be possible to develop a small training programme for TAs. I can see that as more significantly useful than a training programme for teaching staff. They become, often, the enabler, the signposter, a key part of the learning process. And often the TAs don't just 'do things' for the young person, they are also there to deal with the day to day angst that may be there. A mixture of practical things and also some counselling, listening skills and so on"
(Teacher, secondary school).

A few parents and teaching professionals thought that the young person needed emotional support over and above that which the TA could presently offer and some referred to the extra training and information that TAs required. Others thought the emotional issues involved in SCI should be addressed by specialist professionals or that spinally injured children or young people should be able to access one-to-one mentors.

Partnership working

Crucial for a positive school experience are the effective communication and close working partnerships between several parties: parents and carers, school-based staff, other health and social care professionals, and the children and young people themselves.

Information sharing

We asked school-based staff about their access to information on SCI for working with a spinally injured young person. None of the staff we spoke to had general information about SCI and its implications, and only one teacher mentioned doing his own research to fill the gaps:

> *"There's nothing I've come across which are exemplars of good practice or experience from other schools. We've just learnt as we've gone along. I've only found out about SCI from doing my own research"* (Teacher, secondary school).

Instead, many of the school-based staff we interviewed said that they had been given specific information about the individual circumstances of a young person's injury or condition. Much of this information was medically based and included advice on practical tasks such as catheterisation and physiotherapy exercises. For this reason, preparatory meetings that included a range of professionals as well as the child and family, in the term before a child or young person started school, was seen as an essential mechanism for information sharing. As this SENCO commented:

"I think liaison is key. You need to liase with parents, with primary schools, and with the outside agencies, to make sure that you're completely ready when the student arrives. There are always things that need doing in order to make a successful transition. So for me, liaison is critical. And then we have to make sure that the teachers and the teaching assistants know exactly what's happening and what their role in all this is. If I don't do my job properly, then they fail the students and I have to make sure it's all completely ready for September"
(SENCO, secondary school).

This SENCO echoed the view of many of the parents, young people and teachers, who we interviewed for the study, that the SENCO plays an essential role in relation to co-ordinating communication and information sharing in schools.

For schools, another important source of information was the disability advisers and specialist advisory teachers in the local education authorities. Many of the teachers and teaching assistants we spoke to had regular access to these people, as they visited the school on a weekly or fortnightly basis, and school staff highly valued the information and advice they received from them.

Both parents and teachers identified the need for more information. As one primary teacher commented:

"You get snippets of information but if someone would have been able to prepare a leaflet…..a little checklist which said, 'have you considered this?', without us having think what are the issues, what problems there could be"
(Head Teacher, primary school).

It was suggested by both teachers and parents that it would be helpful for schools to have information about SCI and its impact, how to adapt PE

lessons, and the emotional and psychological needs of a young person with a SCI. As this parent said:

> *"It's important for the information for the school…..what they're up against and what they will have to deal with"*
> (Mother of Carly, age 10).

Few school-based staff identified the need for more information: overall they felt that the individual information about specific young people they received was enough. Where problems arose, this was because information about individual children was not shared among staff. This appeared to be a result of confusion surrounding the need for confidentiality. This SENCO summed this situation up when he said:

> *"There are individual records which give information about the injury and how it manifests itself. In terms of getting a student coming in, occupational therapy may come in and do a risk assessment and then it is my job to distribute that information to those who need it, not the whole school. Knowing more about spinal injury wouldn't alter the way we give the support, to be honest. Other more specific information which might change the way we do something, we would expect to come with the student"*
> (SENCO, secondary school).

Ian and his mother experienced what can happen when the requirements of 'confidentiality' are improperly understood and the 'need to know' is too narrowly interpreted. Ian's spinal injury had been caused by a life-threatening illness, for which he had been treated for many months, resulting in high levels of absence. When Ian's mother attended a parents' evening, it was apparent that many of the teachers she spoke to, including his class teacher, did not know why Ian had been absent so much when they complained that he had missed a lot of the curriculum. In this situation, the schools' mistaken interpretation of confidentiality had caused them not to share important

information with Ian's teachers, which was relevant to their responsibility for Ian's learning and general wellbeing.

Partnerships across agencies

Our study revealed many instances where the child's occupational therapist or physiotherapist had played a central role in his or her school life, often by co-ordinating initial visits and meetings, and by assessing accessibility and the need for special equipment. Visits made to the school by such professionals and the information they shared with teaching assistants, about toileting and exercises, were generally greatly appreciated.

Tensions between education, health and social care were also apparent, however. Although one primary school Head Teacher felt that there was greater collaboration across agencies, than before children's services had been brought together, there was still conflict over the funding of equipment and adaptations. Doug, for example, had a chair that he operated himself with his head. After more than 5 years, he had outgrown it. His teacher told us that Doug had completely lost his independence because while a new one was being sorted out, he had to be wheeled around. Doug's laptop had also broken down meaning that he had to revert to using a scribe, again limiting his levels of independence. The teacher went onto reveal tensions between education and health that were directly affecting Doug's access to specialist equipment and, therefore, his independence:

> *"Co-operation between Education and the NHS is complex and difficult. Who's going to pay? The school?"*
> (SENCO, secondary school).

A school nurse we spoke to was concerned at the lack of collaboration between different professionals:

> *"Some of them are brilliant in their own fields but they don't come together on anything"*
> (School Nurse).

One primary school teacher complained that a physiotherapist had advised them to facilitate the child's movement in the canteen using her walking frame, but the teacher felt this was not practical. Under-estimating the need to see the child holistically under the *Every Child Matters* (DfES, 2003) and *Children Act 2004* agenda, she saw her job as educating a class of children. This sometimes clashed with the spinally injured child's health care needs:

> *"We all wear different hats but my primary interest is in how she [the child] is doing educationally. The physio's job is about the physical side and they come and ask 'how many hours has she been using her frame?' But I have 23 other children to look after! I'm all for inclusion but the people who put inclusion policies together have to realise that we are primarily trained to look after education so we can't be expected to look after health needs too. There seems to be an expectation that we are a jack of all trades and that I have to be an expert in this and an expert in that"*
> (Teacher, primary school).

Partnerships between parents and schools

Many teachers emphasised the need to rely on parents' expertise and knowledge about their child's injury. Parents similarly stressed the importance of being open and not always blaming the schools for sometimes getting things wrong. Some parents had sensed the school's anxiety and fear about taking a child with a spinal cord injury because it was an unknown area for them. Parents saw it as their job to inform and educate the school in order to reduce anxiety among staff, which would allow them to work with their son or daughter with greater ease.

As Elizabeth's mother explained, when talking about a school trip that had not been planned as well as she would have liked:

"It could have been daggers at dawn but there's no point in being really aggressive. To be fair, people don't know, do they? They don't know about disabled people and how to cope. People have to have it pointed out to them sometimes. As a parent, you have to communicate; you have to be quite open, I think. You have to get the balance of being firm but not aggressive, I think. You need to ask questions and offer information. It's important not to have a chip on your shoulder – it doesn't do anyone any good"
(Mother of Elizabeth, age 14).

One teacher emphasised the need for an effective partnership between parents and teachers in order to prevent a situation of dependency:

"We [the school] wanted to emphasise to the parents that it was a two way issue and that it was not always about us doing things for Anna. Now we have a super relationship with parents, a shift towards 'what can we do together?'. Otherwise there can be a danger of creating a dependency scenario."
(Teacher, secondary school).

A small number of the parents (n=3) we spoke to had been asked by the schools to become directly involved with developing the school's disability access or action plan, which meant attending meetings at the school. They appreciated this opportunity to use their experience and knowledge to improve the quality of the school experience for other disabled young people. A mother told us that because her son wanted to do GCSE PE, but the school did not have any previous experience of adapting PE for a disabled young person, she saw it as her role to find out about it herself, and to help the school collate this information. She explained her attitude:

"They [the school] haven't got the knowledge and we're the guinea pig. I could go in with guns blazing but I don't think that's what it's about; it's a learning curve and they are willing. I don't expect it to be perfect"
(Mother of Billy, age 13).

Partnerships between young people and schools

For a very small number of young people (n=2), the sense of the school working in close partnership with them was quite striking. Vivien, for example, had been constantly consulted by the school's SENCO about adaptations that were required for the school 6th form building.

For some young people, however, it was more difficult for them to express their views. When asked whether she could raise problems at school, Alison replied:

> *"I don't really like to because I don't know what would happen. I'm not the sort of person who likes to say stuff"*
> (Alison, age 10).

Although they felt able to speak about their experiences and feelings in their annual review, there were often no other mechanisms for this expression outside these yearly events. Instead, many had to rely on more informal mechanisms, such as having a friendly and approachable teacher they could talk to. One boy had been elected Deputy Head Boy. He felt this had given him greater opportunities to express his views and to be consulted because, through this role, he had established a closer relationship with the Head Teacher.

Striving for independence

We have already shown how a wide range of factors influenced a spinally injured young person's level of independence at school. These included the degree to which a building had been adapted for wheelchair use and the availability of fully accessible toilet and changing facilities. It also included the willingness and confidence of school and staff – perhaps especially the TA - to know when to grant the young person more freedom. As we have already

stated, we found no evidence of a correlation between the degree of spinal cord injury and the young person's sense of inclusion in a school or their level of independence. More discussion of the school's ethos and attitudes towards disability will be presented in the next and final section. Here we will focus on examples of both the challenges and opportunities for greater independence for the young people and also their plans and aspirations for the future.

One SENCO had identified independence as a complex and worrying issue for schools to deal with, and was focusing some of their training on this area. She described the school's approach in this way:

> *"Our biggest issue really is allowing students to be independent. And there is a kind of concern because they're a wheelchair user they can't do anything for themselves. So lots of our training is about developing independence and focusing on other students, not just the wheelchair user in the classroom, and this idea of whole class support".*
> (SENCO, secondary school).

Some young people and their parents expressed concern over the schools' need to adhere to health and safety rules taking precedence over a young person's need for increasing independence. Ali, for example, described some of his frustrations over his lack of independence, again attributing much of it to the school's health and safety policies:

> *"I'm not allowed a toilet or lift key, because of health and safety reasons, so I can't operate the lift in case anything went wrong, the toilet too."*
> (Ali, age 15).

We found examples, however, where a school was more willing to 'bend' the rules and consider the need for independence over the need for health and safety. One of these is given below.

Promoting a young person's independence at school

The school decided to prioritise Bob's independence and be more flexible about health and safety rules. By Year 10, Bob was given a walkie-talkie at school and then a mobile phone so he could contact his TA in an emergency. There was an agreement that the TA has her phone switched on but Bob did not so he was able to phone her if he needed to but not vice versa. In his latest peer review, Bob asked if he could go in the lift in the sports hall on his own. He argued that if he were attending as a member of the public, then he would be able to do so. The SENCO listened to his point of view and made the decision to allow him to use the lift independently. His SENCO expressed the approach like this:

> *"For us, the more they can be independent the better….that goes for everyone in the school; we try not to mollycoddle them"* (SENCO)

Bob spoke highly of the school's attitude towards promoting his independence and summed it up in the following way:

> *"The key for me to having a good school experience is introducing independence gradually, perhaps not even gradually…..because it makes you feel good about yourself and confident and you feel as normal as possible. I'm at the stage now where I don't feel that I can't do anything that the others can"*
> (Bob, age 16).

The future

The vast majority of the young people we spoke to held high ambitions and aspirations for the future. A few spoke of how they were starting to train for the 2012 Paralympics, for sports such as basketball or Tae Kwondo. Some were planning to go to University to study subjects, such as law, medicine or psychology, and two were going on to a FE college to study more vocational subjects. One young woman said that she had been greatly influenced by her injury and was planning to study subjects such as counselling so she could go

on and work with spinally injured young people herself. Two were going into work placements to obtain more work experience and on-site training.

We asked the older young people whether they had had careers advice. Most of them had but appeared to be either critical or indifferent about the advice and information they had been given. Only two of the young people mentioned receiving any help from Connexions. One young person said that he had received some very *'dodgy careers advice'* in the past, and another had felt very pressurised by a careers adviser. The adviser had apparently said to her when she was just 13 that she needed to decide what she wanted to do after school as they needed a lot of time to plan ahead. A few young people had received some specialist advice for higher education for disabled people, and two had attended open days at universities to talk about the opportunities for disabled students. Nevertheless, from what we were told, there appeared to be a need for more comprehensive information for disabled young people wanting to go onto further studies or into the work place. As one parent commented:

> *"It's daunting to think that you'll need to go through that learning curve on your own"* (Parent of Natalie, age 17).

Attitudes towards young people with spinal cord injuries

We have left the section about attitudes towards young people with a SCI to the end, not because it is least important, but because it has influenced and permeated every topic about school life as experienced by the children and young people who were central to this study. At the heart of the inclusion of physically disabled children and young people in whole school activities is the conviction that disabled children have the right to be fully and meaningfully included in mainstream education. We found strikingly contrasting experiences of mainstream schooling, many of which we have presented, and markedly varying attitudes among school-based staff about the disabled children who attended their schools. Some parents felt, even before choosing

their children's school, that they and their child were already perceived to be a problem:

> *"We have often sat in a Head Teacher's office and you know they just wish you weren't there; they see you as a bit of a problem and hope you don't come back."* (Mother of Adrian, age 10).

After a good experience at junior school, Adrian's parents were looking for a secondary school with the positive intention that if there was a problem it could be fixed, and a recognition that their son had much to contribute*:*

> *"You can start with the attitude that whatever comes, we'll fix it – you could still talk about all the same things but with a slightly different slant. If you look at his junior school, they're all completely used to the idea of disability; they're used to the fact that he can do anything and what he has given them is of really high value "*
> (Father of Adrian, age 10).

Some of the parents we spoke to stressed the importance of their children being treated as normally as possible and not being over-protective. Felicity's mother, for example, was phoned frequently by the primary school, every time Felicity fell out of her wheelchair. As she explained:

> *"At junior school they wrapped her up in cotton wool. If she had a tumble out of the chair, Felicity would just get back in but they always used to ring me; they used to ring me for the slightest little thing. I used to say to them, do you ring other parents if their child falls over? It was hard to get the message across that she was just like other children"*
> (Mother of Felicity, age 14).

In accordance with the social model of disability, we found that it is not the injury or impairment that disables so much as attitudes, which determine both the facilities and services available and the approach to the young person, which prevails. As this parent put it:

> *"The biggest limitation with any disability is not facilities, it's attitudes. With the right attitudes you can do anything. The right equipment, the wrong attitudes, forget it. The combination of both would be fantastic!"*
> (Mother of Billy, age 13).

One of the most severely impaired young people we saw, Vivien, was enjoying a very positive school experience. While she needed high levels of support to meet her health care needs, she came across as a highly valued and mature young woman. She expressed her opinions freely and was regularly consulted for her views at school. She felt fully included in whole school activities and was growing in self-confidence and independence. Her experience was undoubtedly a reflection of how she was valued within her large secondary school and of its inclusionary ethos. The SENCO there summed up this positive ethos:

> *"This is a huge school but the barriers are very few and far between because of the attitudes of the rest of the school that sees disability not as different or strange. It's about inclusion and it's about making sure the curriculum and the timetabling is inclusionary too"*.
> (SENCO, secondary school).

Here, this SENCO provides an important summary to our main conclusion. This is that a spinally injured young person will only be fully included in mainstream school activities if an accessible school environment is matched with an ethos that has the conviction that all disabled children have the right to the same school experience as their able-bodied peers.

Conclusions and Recommendations

We present below a summary of the main research findings and the recommendations that follow on from these. We finish with a summary of recommendations both for schools and for The Back-Up Trust, so that they can develop their work improving the quality of life for children and young people with a SCI.

Returning to school and other transitions

- Returning to school for many young people who have been spinally injured was an unsettling time where both the environment and people appear unfamiliar. This process can be facilitated by the school staff and friends visiting the child in hospital or at least sending cards if the hospital is too far away to visit, to ensure continuity and to serve as a reminder that they are cared for and have not been forgotten.

- Meetings involving professionals, the young person and their family before the return to school are seen as beneficial in this transitional period. It is important that young people are included in these meetings. This allows the opportunity for them to express their feelings and wishes and keeps them in the picture.

- Visits to the school to re-establish friendships and, accompanied by a physiotherapist, to 'test out' accessibility are also useful in preparing young people in returning to school.

- Delays in returning to school can sometimes occur while a teaching assistant or carer is being recruited. The Back-Up Trust may wish to consider developing a checklist or generic job description to make this process quicker for schools. The list should not, however, be prescriptive, but open to adaptation according to the needs and wishes of the child.

- A small number of children are accommodated in unsuitable surroundings or have to move schools altogether because their school buildings are inaccessible for a wheelchair user and there are delays in obtaining funding and carrying out necessary adaptations.

- Some children were transferring into secondary schools, which were clearly not ready or prepared for them. Transferring from primary to secondary school, therefore, requires schools to forward plan in order to meet the needs of spinally injured and other children using a wheelchair.

- The transition could be facilitated by the provision of specific information on SCI to schools preparing to receive such a child. It is also important that schools hold a meeting early on in the last year of primary school, Year 6, for the young person, family, education and health professionals, in order to prepare for the child's admittance and plan for necessary adaptations. The opportunity for the young person to have at least one full day visit to the school during Year 6 would also facilitate this process.

- The first impression that disabled young people and their families when they first visit a school is crucial. This visit should be carefully prepared with regard to access, the information to be supplied and crucially, the staff, who will introduce and welcome the child to the school.

Premises and equipment

- Almost all the children and young people in the study reported not being able to access some areas of the new school. These areas included certain classrooms, the dining hall, or the library, for example, which were either upstairs or had steps within them.

- Steep ramps and classrooms that were too small for manoeuvring a wheelchair, were common problems experienced by the young people.

- The funding for and speed at which, adaptations to school buildings were carried out varied considerably, and appeared to depend on how a proactive a school was and the support of the local authority.

- Having specialist equipment made available for spinally injured young people was not straightforward. Although equipment such as adjustable tables and workstations were essential for some young people, for some it singled them out and restricted their independence. It appears, therefore, that the professionals involved in providing specialist equipment must carefully assess its need in close consultation with the young person,

family and teaching staff, and not make assumptions about what is required.

- Special units for disabled children within mainstream schools that can be used for 'quiet' periods can be beneficial for young people with a SCI, as long as they are consulted about whether or not they would find their use valuable.

- So-called 'disabled' toilets were often inadequate in size or shape or were free for anyone in the school to use. Schools should ensure that the disabled toilet is truly accessible to a wheelchair user and is only used by disabled students and staff, by issuing a radar key to them.

- Some parents identified the lack of disabled parking spaces at school, which hampered the child's punctual attendance.

Friendships and inclusion in school activities

- While physiotherapy rooms at schools can benefit many young people with a SCI, careful consideration needs to be given to when physiotherapy takes place, so young people do not miss out on too many lessons or social times.

- Making and sustaining friendships at school was challenging for many of the young people who participated in the study. Younger children and young people appeared to face more difficulties in their peer relationships than the older teenagers did. This may as a result of the greater experience and self-confidence of both the injured young person and their peers.

- School staff should be especially aware of the need to support friendships, for example, by practical measures that avoid separating disabled young people from others and by educating non-disabled students about inclusion.

- The ethos of the school regarding disability and inclusion and the amount of information and preparation given to the other children determine, to some extent, the quality of friendships a physically disabled child has in the school setting. Schools need to use Personal Health and Social

Education (PHSE) classes and assemblies for information giving about the spinal injury, its implications and how best to help the young person.

- Having friends push your wheelchair can be beneficial for many young people and their friendships. Although schools are understandably wary about other children pushing a wheelchair at school, the decision to ban this practice needs to be taken in close consultation with the young person, their parents, and based on individual circumstances.

- Lunchtime at school is an important time for socialising. Many schools want physically disabled young people to leave their lessons early so that they can get to the dining hall before it becomes too crowded. Although this might meet health and safety regulations, leaving before the end of lessons can mean missing the setting of homework and can result in young people feeling singled out and socially isolated.

PE and sport

- Some young people with a SCI experienced exclusion from PE and sport at school, as a result of inaccessible fields or gyms or either equipment or activities, which were not adapted specifically for them. In contrast, other young people felt fully included in PE lessons and felt that activities were adapted to suit their needs, so that they were not side-lined. This difference appeared to be determined by the attitudes and knowledge of PE staff.

- Some children and their parents complained of difficulties in participating in school swimming sessions, such as the lack of suitable changing facilities, a hoist, accessible transport to the pool or the water being too cold.

- One school organised a demonstration of wheelchair basketball so all the able-bodied children could join in; this was greatly appreciated by everyone involved.

- The inclusion of disabled children in PE needs to be addressed by every school. The Back-Up Trust should consider preparing information for

schools, in co-operation with universities providing PE teacher-training courses and with sport organisations, such as Sport England.

Transport and school trips

- Many of the young people and the parents interviewed had experienced problems with their local authority transport to and from school. These problems included being picked up very early and being dropped off late, or the taxi not turning up at all.
- The lack of flexibility with transport was also a difficulty experienced by many, so that young people could not always stay late for clubs or to see friends after school.
- A small number of young people had more flexible arrangements: their driver would also transport a friend sometimes, or would collect them at a different time, if necessary. This was facilitated, in most circumstances, by having the same driver allocated to the young person, so that s/he got to know the young person and the family.
- Most of the young people had experienced difficulties with going on school trips, usually because of transport difficulties. Disability accessible coaches were either unavailable or the cost was prohibiting schools from using them.
- Schools need to include all disabled students in school trips, by law (DDA). In order to do this, schools need to plan ahead carefully and have a checklist to remind them that all transport and venues have to be checked before booking for accessibility.

The role of the Teaching Assistant

- The relationship between the Teaching Assistant (TA) and the young person with a SCI was found to be a crucial one, but not one without its challenges. Young people and their parents appreciated Teaching Assistants who were caring but not over-protective and who were sensitive to the young person's need to socialise without interference.

- Having clear boundaries as to the role of the TA was also found to be essential. Many young people felt that although they appreciated young TAs who were fun, at the same time, they did not see them as their friends. Providing space for young people, and knowing when to 'back off' was as important as knowing when to be there.

- Teaching Assistants have a broad role to play in supporting children and young people with a SCI. It is important that they understand that their role is not just about practical tasks such as handling and toileting, but also listening, and, providing emotional support as required.

- We found that the training available to Teaching Assistants is very limited and focuses on practical issues such as manual handling, using a catheter and a hoist. There is a need for more training on the implications of having a SCI, not just about the physical implications but also about the impact on a young person's emotional and psychological wellbeing.

Co-operation and information sharing

- Although effective information sharing and close partnerships across agencies and between schools, parents and young people is crucial for a positive school experience, we found evidence of challenges and tensions in some of these partnerships.

- There is a lack of relevant information about SCI and its impact available to schools. Many teachers and parents recommended that information and guidelines on subjects such as the teaching of PE and the emotional needs of a child with a SCI, would be helpful.

- We found many examples of the occupational therapist or the physiotherapist playing a central role in facilitating a spinally injured young person's place at school. However, generally there are still tensions evident between health and education, especially in regard to the funding of specialist equipment. A clash of attitudes about whether a child's educational or health needs should be prioritised was also evident, implying a lack of understanding by some professionals of the holistic philosophy underlying the *Every Child Matters* agenda. This should be an

area of on-going development for children's services and Primary Care Trusts.

- Partnerships between parents and schools were generally close and positive. This was particularly apparent when the schools were not defensive about what they did not know, and parents did not blame them when things were not done as well as they would hope. Partnerships worked well when both parents and schools were open and receptive to learning, sharing information and expertise.

Independence and participation of young people at school

- Some young people were consulted for their views about disability issues at school as well as about their own experiences at school. However, for many young people there were no formal mechanisms for this outside their annual reviews. Both formal and informal measures allowing young people to express their experiences and requirements should be developed by schools and children's services.
- Spinally injured young people's levels of independence at school were determined by a wide range of factors, including the accessibility of the physical environment, the availability of suitable toilet and changing facilities, and the confidence of the TA to allow the young person more freedom.
- Independence at school was also determined by the willingness of the school to be flexible about health and safety rules and to consider each situation based on the individual circumstances. One school, for example, gave a young person a mobile phone, which he could use in case of an emergency. This meant he could move around the school freely, use the lift and go to the toilet without assistance, in this way promoting his independence.
- The independence of disabled young people should be given a high place in the school's policy and practice regarding inclusion.
- Young people with a SCI are first and foremost individuals whose experiences and feelings are specific to them. Young people should,

therefore, have the opportunity to communicate openly with their peers and staff about their needs and wishes at school, for example, in relation to how much independence at school they wish to have and whether they want others to help them in their wheelchair.

Careers Advice

- Most of the young people were highly ambitious and their future plans included training for the Paralympics, studying at University or FE colleges.
- The young people were either critical or indifferent about the Careers Advice they had been given, and felt the need for more comprehensive information about the opportunities open to them.

An essential requirement

- Above all, the ethos and attitude of the school towards disability largely determines the quality of the school experience for spinally injured children and young people, including their levels of inclusion in whole school activities and independence.

Summary of Recommendations

Recommendations to schools

1) To ensure a meeting involving the child, parent, school and involved health professions takes place before a child returns to school after hospitalisation or when transferring from primary to secondary school.

2) To ensure that annual reviews take place and that there are more frequent opportunities for the views and suggestions of children and young people to be heard.

3) It is important that there are mechanisms in place for both young people and their parents and carers to raise issues with ease if and when they arise outside these annual meetings. This might mean ensuring that both the young person and the family know exactly who to contact and the best means of doing this.

4) Schools are advised to ensure that their open evenings and subsequent visits for disabled young people are both welcoming and positive towards the young person and their family.

5) Adaptations should be carried out as quickly as possible to ensure that children who use a wheelchair are able to access all areas of the building.

6) Specialist equipment can be very important for children with a SCI but some young people prefer not to use it as it singles them out or they feel it is unnecessary. The need for specialist equipment should be assessed based on individual circumstances and preferences.

7) Children and young people with a SCI have the right to be included in whole school activities. PE needs to be adapted for disabled children and PE teachers should seek advice or training about how best to adapt PE lessons for wheelchair users.

8) PE Teachers need access to both funding for specialist equipment, such as lower nets and larger rackets or balls, and specialist guidance and training for teaching PE to wheelchair users.

9) All children and young people, regardless of disability, have the right to attend school trips. Schools need to plan ahead carefully to ensure that

both transport and venue is accessible, and use the school budget to pay for extra costs, if necessary.

10) Schools should also ensure that there are enough disabled parking spaces and monitor their use so that they are available for use by those who need them.

11) Teaching assistants need to receive more training and information about SCI and its implications, including its emotional and psychological impact.

12) Teaching assistants have an important role to play in promoting a young person's independence. By consulting the young person and his or her family, the TA should take gradual steps to give the young person more freedom, in order to socialise with his or her friends alone, for example.

13) Schools need to be more flexible about their health and safety rules so that young people with a SCI can be more independent. They should offer the use of a mobile phone to older young people so that they can call someone in an emergency.

14) Pushing a friend's wheelchair might also be an important part of social interaction so this should not be banned without first consulting the child and family.

15) Physically disabled young people need more comprehensive specialist information about opportunities for future careers and further studies.

Recommendations to transport companies

1) Transporting a young person to and from school should have a degree of flexibility so that they are able to attend after school clubs and go and see friends after school.

2) Having the same driver as much as possible provides the young person with continuity and facilitates the flexibility of the arrangements.

Recommendations to The Back-Up Trust

1) To fund a Schools Officer post who could help schools implement many of these recommendations, such as ensuring there is a planning meeting prior to school admission, adaptations are happening and to advise PE

teachers. A large part of their role would also be to train teaching assistants and prepare guidelines and information leaflets for schools.

2) To develop some guidelines for schools to aid the development of job descriptions and recruitment of teaching assistants for children with a SCI.

3) To develop guidelines that outline the role of the teaching assistant.

4) To provide more information about further and higher education, and for future careers for young people.

5) To provide more information to parents about what to expect after their child is injured, in regard to the process of assessment and statement of special educational needs carried out by the local authority, available services and benefits.

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Appendices

Information leaflets

Children and young people with a spinal cord injury (SCI) and their experiences of mainstream school

Abigail Knight, Pat Petrie, Patricia Potts and Maria Zuurmond

The Back-Up Trust has asked the Thomas Coram Research Unit at the Institute of Education, University of London to carry out a piece of research for them to help them develop their work in schools. This is so The Back-Up Trust can help improve the quality of mainstream schooling for children and young people who have experienced a spinal cord injury (SCI).

To do this the research aims to find out:

How children and young people with a SCI experience mainstream school (including primary and secondary). What have been the challenges and barriers that they have faced? What has helped and been positive experiences for them?

To investigate the school's experience of working with children and young people with a SCI. What are the main challenges and what helps them work effectively and sensitively with young people with a SCI?

To identify the experiences of some parents of children and young people with SCI in relation to schooling; what, from their point of view, has helped or hindered their son/daughter's experience of mainstream school.

To gather examples of the resources, such as documents/guidance, relevant to working with children with a SCI, employed by school.

The study will be conducted between January and June 2008 and will involve:

- Visits of up to 40 children and young people with a SCI across England and Wales, preferably in their school setting.
- Interviews with up to 40 school staff working with young people with a SCI.
- Discussions with up to 40 parents of young people with a SCI
- Discussions (mostly telephone) with up to 10 other professionals working with children with SCI.
- A report of research findings and recommendations will be produced for The Back-Up Trust in July 2008. A short summary

of the research findings and recommendations will be produced for research participants and other interested parties.

For further information, please contact: Sam Byles at The Back-Up Trust on 020 8875 6721. Email: sam@backuptrust.org.uk or Abigail Knight, Thomas Coram Research Unit,

We need your help!

What's your school like?
How easy is it to get around?
Do you feel included in all the school activities?

Researchers from the Thomas Coram Research Unit (University of London) have been asked by The Back-Up Trust to find out how you and other young people with spinal cord injuries experience school. This is to help The Back-Up Trust to improve school for young people with SCI.

We'd like you to show us around your school and tell us what it's like, both the good and the bad things. We hope you can take a few photos for us too!

You can pull out at anytime, without saying why. Everything you tell us will be confidential and you or your school will not be mentioned in the report that we write. You will receive a £5 cinema voucher and a summary of what the research found out and the recommendations that were made. You will also be helping other young people with a SCI in the future!

We hope you can help us! If you don't want to take part then do let us know! Otherwise Abigail, Maria or Patricia will contact you early next year. If you want to know more contact Sam at The Back-Up Trust on 0208 875 6721 or Abigail at the Thomas Coram Research Unit on 020 7612 6458 (**a.knight@ioe.ac.uk)**.

Get yourself a £5 cinema voucher!

Topic guides

Topic guide – children and young people

Introduction

Remind them about purpose of research and give them another copy of leaflet.

Reassure them about confidentiality (unless they are at risk in some way) and anonymity in final report.

They will receive a summary of findings and recommendations later in 2008.

Check they are still OK to be take part. Remind them they can stop at any time and do not have to say why.

Remind them about what we'd like them to and they can choose what they would rather do (depending on what has been agreed with the school before hand):

1) Show us around school, showing (and possibly taking photos) of what is good/bad about school (eg. physical environment). Be clear they cannot take pictures of other people.
2) Interview (can do this as well as 'tour' or just interview)

Remind them that we will also be talking to a member of staff (but not necessarily about them personally - this is to gather information about what it is like for school for meet the needs of someone in wheelchair in general terms).

Also remind them that we will be talking briefly to their parent/carer about how they are getting on in school since their injury. (NB we may have already done this at home visit prior to this school visit).

Ask permission to be taped.

Remember to give them £10 voucher.

Thank you etc!

Topic guide

Name:

DOB:

School:

Ethnicity:

How long?
   1) **At this school?**
   2) **Since injury?**

Tour

If they would like to show us around school and talk through (and take pictures on Polaroid or digital camera) any of the following:

   Positive aspects of the school
   Obstacles
   Challenges
   Barriers
   Things to improve/change

Interview

   1) **Tell me what it was like returning to school since your injury?**
      (prompts: being at school again, seeing friends, teachers, physical environment, how s/he coped emotionally/practically);

   2) **Tell me about how school is NOW?**
      (different from when you first came back? If so, why? In which ways?

   3) **What do you like about school?**
      (prompt: relate to their disability; explore areas like physical environment, attitudes towards them at school, relationships with teachers and peers; inclusion in whole school activities like assemblies, trips, PE and other physical activities)

   4) **What or who helps you at school? In which way?**
      (prompts: as above)

5) What things at school are difficult or you don't like?
(prompts: relate to disability. Also same prompts as above. Any feelings of exclusion?)

6) What would improve your experiences at school?

7) Are there things the teachers and other staff at school need to do to improve your school experience?
(eg. more information, training about physical disability, more staff?)

8) Any other recommendations?

9) **What are you hoping/planning to do after this school?** (prompts: have they had vocational/career support/advice about transition to college etc)

10) Anything else to add about your experiences?

Check if they would like to help us with research findings summary for young people – this would mean commenting on it by email. If yes, ask for their email address

Email:

Thank you!

Give voucher

Topic guide – parent or carer

Name:

Address:

Child's name:

Remind them of aims of project, confidentiality, anonymity, that they will receive research findings later in year.
Give leaflet
Check they are still Ok to go ahead with interview and to be taped.

1) **Tell me what it was like for both you and your son/daughter (use name) when s/he returned to school after their injury?**

   - How long between injury and return to school?
   - How did s/he settle?
   - What helped this process?

1) **How is _____ getting on at school now?**
   (Prompts: positive things? Challenges? Barriers? Explore physical environment, friendships, inclusion in activities)

2) **What things or people help _____ at school?**

3) **What things or people hinder?**

4) **What do you think the school needs to do to meet the needs of children/young people who use a wheelchair?**

5) **Recommendations to improve your son/daughter's experience at school?**
   (prompts: training, information, attitude change, resources and so on?)

6) **Anything to add?**

7) **Is there another professional working closely with your son/daughter who we could talk to? If yes, please get contact details.**

   THANK YOU!

Topic Guide - Teachers/School staff

Name:

School:

Address:

How long a teacher?

How long have you worked with a child with a SCI or wheelchair users?:

Have you heard of The Back-Up Trust? If so, how?

Introduction

Remind them about purpose of research and give them leaflet (ie. to help find out how schools manage working with children with SCI and to help The Back-Up Trust improve school provision for them).

Reassure them about confidentiality and anonymity in final report and recommendations to The Back-Up Trust.

They will receive a summary of the research findings and recommendations in summer/autumn 2008.

Check they are still OK to be interviewed.
Ask permission to be taped.

TOPIC GUIDE

Discuss the following issues in relation to children using wheelchairs more generally and not specific to the child with a spinal cord injury. Ie. the discussion needs to be general rather than personal.

A) Opportunities and Challenges

What have been the main opportunities/positives and challenges about working with a child who uses a wheel chair?

(for you and the class/whole school).

Prompts:
a) The physical environment
b) Friendships
c) Whole school activities (such as assemblies, school trips)

B) Training and support

1) What training, if any, have you had about working with a child with a spinal cord injury? Or working with a wheelchair user?

Prompts:
a) Training provided by whom?
b) Length of training
c) Name of course
d) Brief content of training
e) View of training?

2) What are the challenges in obtaining relevant training?
(prompts: resources, getting cover, relevant training being available, other?)

3) What type of support are you receiving in relation to working with a child with spinal cord injuries?
(prompts: are there any links between school and on-going rehabilitation? Are there other professionals coming into school to visit the young person? If so, would it be possible to have their contact details for the study?).

4) What gaps do you think there may be in training and support for working with children with spinal cord injuries/children who use wheelchairs?

5) What are your recommendations to improve these areas, from your experience?

D) Information and resources

1) **What information and resources (eg. leaflets, documents) do you use to help you work with a child with a spinal cord injury/child who is a wheelchair user?**
(Prompts: written information/internet/other?)

NB. Ask to see copies of any relevant copies of anything they use. Please note any references and/or photocopy them as we will need to get copies of these to show The Back-Up Trust.

2) What information/resources have been most useful? What would you recommend to other schools?

3) What gaps in information and resources for working with children with spinal cord injuries do you think there are?

<u>E) Recommendations</u>

1) From your experience, what would you recommend to help improve the quality of school provision and help you work more effectively with:
a) children with a spinal cord injury;
b) children who use wheelchairs more generally.

2) Do you have anything to add?

Thank you.
Remind them they will receive a feedback summary in summer/autumn 2008.