



1. Understanding Inclusive Education

1.4 What do children and young people say?

Introduction

Listening to the school experiences of children and young people who have spinal cord injuries is critical to understanding how to make inclusion happen. By considering the perspectives of children and young people who have already gone through the process of inclusion, we can better grasp what difficulties they face, what strategies helped to welcome and include them and the importance of involving them in the process.

Most research on children and young people with spinal cord injuries focuses on medical aspects of their lives. Little has been done around their social and school experiences. Recognising the vital importance of these perspectives, Back Up commissioned the Institute of Education to conduct research into these areas in 2008:

[The school lives of children and young people with a spinal cord injury](#)

The report found that ‘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.’ Creating an inclusive ethos and school culture is the most important step schools can take when welcoming a student with a spinal cord injury back to their school community.

Other findings from the report are found throughout this toolkit in relevant sections. Highlights are summarised below according to different categories:

1 Returning to school

- Most students in the study obtained their injury in childhood or adolescence, meaning they had to return to the school they had previously attended. For many, returning to school was ‘a difficult and sometimes traumatic event.’
- The process of returning can be improved through hospital visits and communication, early meetings with the young person and family to discuss requirements, and support to re-establish friendships.
- Adaptations and adjustments necessary for appropriate access to school should be made as quickly as possible to ensure a sufficient welcome for the student. This often requires schools being proactive and supportive local authorities.
- Many students who return to school report still not being able to access some parts of the school.
- Adaptations that had been made to schools were rarely straightforward. Children and young people often found that ramps were too steep, specialist equipment restricted their independence, and ‘disabled’ toilets were inadequate or unavailable.

“ **I was extremely scared about going back to school. I just didn’t like the idea of going back. My school were really good. They were eager to get me back. The teachers were understanding about everything like if I wasn’t well or couldn’t go in or if I had a hospital or doctor’s appointment. They understood that it was not going to be the same as before. They gave me extra time to do things.** ”

Danielle, 17

2 Social life and friendships

- Health-related activities like physiotherapy sometimes interfered with social time and lessons.
- Maintaining and making friendships was seen as more difficult for the children and young people with spinal cord injury. The ethos of the school, well written policies and procedures and efforts of staff to include (rather than separate) students had a positive effect on friendships.

3 Physical education and physical activity

- Many activities for children with a spinal cord injury tend to be sedentary and set at home. There is a need for more unstructured play and outdoor activities, in addition to structured recreation.
- Some young people with a spinal cord injury felt excluded or sidelined from PE and sports. Others felt more included, and the 'difference appeared to be determined by the attitudes and knowledge of the PE staff'.
- School swimming activities posed particular challenges, including appropriate changing facilities, transport, hoist and water temperature.

4 Transport and school trips

- Transport to and from school was reported to be a problem for many young people. Problems included very early pick up, taxis not turning up, and lack of flexibility.
- Issues with transport often impacted negatively on students' ability to attend trips outside school.

5 Role of Teaching Assistants

- The role and relationship of teaching assistants (TA's) is a critical one in the inclusion of children and young people with spinal cord injury. Qualities that children and young people liked to have in teaching assistants included a caring nature, clear boundaries and sensitivity to their need for socialisation without being overly protective.
- TA's need training that reflects the multi-faceted nature of their jobs. In addition to appropriate training on practical issues like manual handling and using a hoist, they also need information on how to support young people's social, emotional and psychological well being.

6 Co-operation and information sharing

- The cooperation between professionals involved in a young person's care and return to school is essential but also difficult to manage. Tensions were reported to exist between health and education, particularly in regard to funding specialist equipment and how to prioritise health and education needs.
- Partnerships between schools and parents were important and succeeded when both were 'open and receptive to learning, sharing information and expertise.'



I was more scared about how people would react to me and how I would be able to make friends. I found it really difficult at first to make friends.

Laura, 18



My advice is to talk to the student, don't feel bad or embarrassed or shy about talking to them about their spinal cord injury. This might seem like a little thing but it can make a huge difference to the student. Asking them what they want is so important.

Ben, 17

7 Independence, participation and ambitions of young people at school

- For many young people, there was little consultation about disability issues at school beyond their annual review. These should be developed in schools aiming to include children with specific requirements so that they have a say in how independent they are and how they want others to help them.
- Independence levels of children and young people with spinal cord injury varied significantly depending on many factors, such as accessibility of the school, confidence of the staff and TA's to allow for independence, and the willingness of the school to be flexible about health and safety rules.
- The independence and participation of disabled young people should be emphasised in a school's inclusion agenda.
- Most young people interviewed were 'highly ambitious and their future plans included training for the Paralympics, studying at University or FE colleges', but also wanted more comprehensive, better quality careers advice.



When I went to high school I was wrapped up in cotton wool, not by my parents but by the teachers, by the school in general and the system. The attitude was that I was in a wheelchair and that I couldn't do anything and that I'd need loads of help. I wanted to be just like everyone else and that prevented it.

Laura, 18

What needs to change in schools to make sure everyone is included?

A focus group was run by Back Up involving young people with a spinal cord injury, a group of young volunteers and Back Up volunteers. The focus group looked at the question above and responded with the following:

Attitudes

- Asking individuals what they want!!
- Recognition that it is our needs and requirements (not our wants) which need addressing, and providing for them, so that people are not made 'special', or at risk of being bullied.
- Sensitivity to pupils who, for reasons of their own, do not want to be included in all areas possibly because of their needs and reactions to noise, light, crowds etc.
- Learning and teaching on non-judgemental attitudes.
- Learning and teaching about minority issues and groups in a worldwide context.
- Team building for kids as well as teachers!
- Many role model staff and visitors to schools of people with a wide range of needs and lifestyles.
- No separation of disabled and non-disabled pupils from the start, so that all are seen as individuals.
- Sport used to mix people socially and ability wise so they learn from each other and enjoy themselves together.

Disability awareness

- Training for teachers, support staff and all people who work in schools on disability awareness and equality.
- Specialist staff who can identify issues and difficulties, and make sure pupils are supported.
- Fun and participatory teaching and learning techniques.
- Learning about disability issues which is taught by disabled people themselves.
- Very sensitively handled provision of learning support - not in your face!
- Willingness to join the fight for our rights and the rights of our peers in the light of the Equality Act.

Access and equipment

- Braille, lifts, accessible loos, interpreters, note takers etc.
- Good quality equipment which is helpful, but not intrusive of our making of friendships.
- Access to grants (via internet sources and teacher 'know how') so that we can look after a lot of our own needs.
- Well designed spaces and buildings to enhance everyone's participation.
- Space in schools for ANY kids to retreat a little when they need to.
- Good access (including transport) to high quality out of school experiences, and especially school trip and journeys nobody left out!
- Links between schools and groups of staff (teachers, supporters etc.) locally and nationally.
- School councils with equality of representation.
- Medical and therapy appointments during out of school hours, so as not to interfere with schooling and keep people the same

All information from

Knight, A, Petrie, P, Potts, P and Zuurmond, M. (2008) [The school lives of children and young people with a spinal cord injury](#). Thomas Coram Research Unit, Institute of Education, University of London. Report to Back Up.