



## 3. Practising inclusive education

### 3.4 Involving children, young people and families

## Introduction

Involvement of children, young people and families is an intrinsic part of inclusion. While the assessments and opinions of education and health professionals will also be vital to the coordination of including a child or young person with a spinal cord injury, it is the school's response to the experiences of that individual that will determine the success of his or her inclusion.

“ **My advice to staff 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

The most important thing to remember about the inclusion of a child or young person with a spinal cord injury is to ensure they are at the heart of the process.

“ **The absolute key thing is person-centred planning so ask the child. This is where schools often go wrong because they're looking for this pill that someone else is going to give them where actually they have the power themselves to change what they are doing. That young person is the absolute number one best person to tell them what they need. And people forget that. They're waiting for some expert of genius to come along and tell them where actually the expert is right in front of them – it's a young person.**

Nigel Utton, Headteacher, Bromstone Primary School and Chair, Heading for Inclusion

The process of participation and involvement will depend on a number of factors including the age of the child or young person, their personality, how they are coping with their injury, and their previous experiences of school life, among other factors. But regardless of all these factors, the characteristics of this participation should always be the same: consistent, genuine, transparent and responsive. Legislation supports children's participation in all matters affecting them, that their views are respected and their best interests are considered at all times in article 12 of the [UN Convention on the Rights of the Child](#) (ratified by the UK in 1991).

Children and young people have said repeatedly that they want to be consulted on their own lives. From an Institute of Education report on the school lives of children and young people with spinal cord injuries:

Involving parents and families is also very important for the inclusion of their child. Not only will families be able to provide valuable insight and information into the requirements of the child, but they will need to feel involved so they can properly support their child's adjustment. Additionally, families will also likely be struggling with the stress and trauma of a spinal cord injury and will greatly

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**Most of the things I've learned are by talking to the child. They're the experts on their needs and they can help you quite a lot.**

Dr. Phil Vickerman, Professor of Inclusive Education and Learning, Liverpool John Moores University

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**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, 18\*

appreciate the support of an inclusive school environment that feels welcoming and open to their child's new needs.

## Strategies and methods for involving young people and their families

**1** Support children and young people to participate and contribute in ways they are comfortable with. It may be daunting and difficult to make decisions related to their new circumstances, so sensitivity, encouragement and responsiveness are important characteristics of the process of involving the child or young person.

“ **Following our student's trauma, she was surrounded by a lot of professionals involved in her rehabilitation and the process of integrating back into home and school life. The presence of so many people is to help but it can also be overwhelming. Suddenly an awful lot of people to deal with. At school we were aware that this can all be 'a bit much'. We felt it was important to encourage our student to make her own decisions and express her views but only when she specifically wished.**

SENCO, Gloucestershire

**2** Organise a meeting involving professionals, families and the child or young person before they return to school. This meeting could communicate the child or young person's requirements, determine how the school should respond to these and assess physical access alongside professionals like an occupational therapist. Children and young people should be given the option to attend and participate in these meetings.

**3** Hold regular review meetings to go over the current support plan, how the student is doing and any further adjustments that need to be made. Include the child or young person and family in review meetings and use them as times to discuss goal planning and future decisions, any classroom concerns, transport issues, or access or equipment problems. See section 2.2 for more information on integrated support models.

**4** Consult with the parents and the young person about accessibility and involve them in the planning of any changes to buildings.

**5** Be clear and consistent in your communication with the child or young person and their family. They should know what to expect from the school and be able to rely on it.

**6** Work with the child and young person in the selection and use of specialist equipment. Some students with spinal cord injuries in a recent study on their school experiences reported feeling singled out by being given equipment they didn't actually feel was necessary.

“ **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. It meant I was restricted where I sat every lesson. I had to sit at the front which was annoying.**

Julie, 18\*

**7** Inform parents of how you have managed the practical issues, particularly those related to health and medical needs. (E.g. What medical staff are available? What

1:1 support will the child have? How will you manage their catheters and any manual handling requirements? What happens if the child falls out of their wheelchair? How will your child participate in physical education?)

**8** Encourage parents to share any relevant aspects of the child's medical care, though there may be some hesitation or resistance to be open about the issues the child or young person is facing. You should be sensitive to this, particularly as the entire family has experienced significant trauma. Providing privacy and a comfortable environment can help in situations where difficult issues are discussed. Parents are important sources of information – and this communication will also help them remain involved in their child's support and education.

**“ We try to make sure the process of returning to school is led by child or young person. For example, discussing with the child and the family what they would like said to the rest of the school so that at all points, the child or young person is aware of what is going to be said and is happy with it. We arrange visits back to school while the young person is still in hospital completing their rehabilitation programme and focus on helping them keep in touch with their friends and teachers. We try to continue with the same work their class would be doing so we can send it back to school for the teacher to respond to. Hopefully this helps everyone feel they are still in touch. We have used video conferencing to keep young people in touch with their own schools but have found that the young person needs time to adjust to their injury and feel comfortable with the process.**

Jo Jones, Teacher in Charge, Blueprint Hospital Teaching Service, Stoke Mandeville Hospital

Suggestions from a Back Up workshop (involving peers of a young woman in the process of re-inclusion, October 2009)

- 1** Find the best ways to elicit the views of the young person to be included, or re-included.
- 2** Take into full consideration the views of the young people in relation to all aspects of planning for their inclusion, or re-inclusion.
- 3** Support the young person in thinking about how they want to plan for their inclusion if they are unsure about the process - i.e. explore how peers/staff may learn about spinal cord injury; if they would like to be present at meetings with professionals coordinating their care and if not, explore the option of an advocate who can voice their ideas and concerns.
- 4** Recognition that focussed thought, learning and planning do need to take place to make successful inclusion possible, even though the aim of inclusion is to ensure an equal playing field, and 'business as usual' situation for everyone.
- 5** Best ways to involve peer students in the inclusion process need considerable thought, recognising that opinion will always straddle a wide range of views and perspectives. Creating a space for lively dialogue is much more important for full agreement.
- 6** Balancing the needs of students to be included with the needs of their peers, is vital, recognising that...