

Senate inquiry on education of students with disabilities

Submission from SBH Queensland

SBH Queensland is a community organisation which was formed in 1969 to provide services to people with spina bifida and hydrocephalus in Queensland.

The majority of its government funding is provided by Education Queensland and the Commonwealth Special Education Program. As a consequence, the main activities of the association fall under the rubric of education, and most of its objectives are along the lines of improved educational outcomes for students with spina bifida and hydrocephalus.

SBH Queensland employs eleven allied health staff in these programs. They comprise occupational therapists, physiotherapists, social workers and teachers.

In addition, two staff are employed to provide services to teenagers and adults post school. These two staff are in an excellent position to see how the benefits and effectiveness of programs carried out during the school years carry over into the students' lives after school.

SBH Queensland has a very good working relationship to staff of Education Queensland, independent schools and the staff of educational settings children attend prior to formal schooling. The association also is very pleased that its contribution to the education of students with spina bifida and hydrocephalus is widely recognised and has been supported by funding from Education Queensland and the Commonwealth Special Education Program for many years.

The information in this submission arises from the experience of SBH Queensland staff working in this area for many years. No formal research projects have been carried out to further investigate or confirm these points. Also, the experience only relates to the education system in Queensland.

The issues can be grouped into four themes.

1. The difficulty of getting appropriate assistance for students with learning disabilities in education
2. The lack of available support
3. The effect of increasing bureaucratic demands on SBH Queensland, and
4. Some other issues noted by staff in their dealings with children with spina bifida in education.

The difficulty of getting appropriate assistance for students with learning disabilities in education

The effects of spina bifida and hydrocephalus on children are quite varied. Broadly speaking, there are two areas of difficulty – the physical and the intellectual. The physical side of the impairment involves difficulty with mobility and incontinence. The intellectual side involves difficulty with a number of intellectual skills which are commonly labelled learning disabilities. While the severity of the physical problems is usually proportional to problems with the intellectual problems this is not always the case. On the one hand, there are people with spina bifida who have very mild physical disabilities, but who have very significant intellectual deficits, and on the other hand some with very significant physical disabilities who have no intellectual deficits at all. Another factor is that the learning disabilities associated with spina bifida and hydrocephalus are neurologically based, ie they will not improve with time.

1. In the Queensland education system children are ascertained and receive support for physical disability through a number of advisory teachers for physical (and other) impairments, but support for learning disabilities is assessed and supplied on a school by school basis. The advisory teachers who often have a good understanding of the learning problems of children with spina bifida and hydrocephalus are not involved in the assessment and support of children with learning problems. This often means that support for the children's learning is often overlooked or the problems are not sufficiently well understood to provide adequate or helpful support. This is more often the case

when the learning disabilities have a greater impact than the physical disabilities, in which cases the advisory teachers may not be involved.

2. For similar reasons, there is very little support for children who have hydrocephalus as their only impairment. These children have no physical disability, but do have learning disabilities.
3. The social, emotional and developmental problems brought about by the children's learning disabilities grow because they are not picked up early enough. Many school staff prefer to wait for a formal assessment such as the Year 2 diagnostic net, when a whole year has been wasted. An earlier intervention would have assisted these children to develop more normally, both academically and socially.
4. A lack of knowledge of preschool teachers and child care workers on the learning disabilities associated with spina bifida and hydrocephalus means that children with these impairments are seen as developing normally (just the same as the other kids). However, their behaviour will not change with maturity (just like the other kids), and requires specific intervention at an early age to help children develop more normally.
5. The problems children have with continence are very obvious in the classroom. There is no ignoring the problems when children have bladder and bowel accidents. In the short term these require urgent attention and in the long term constant vigilance and adherence to the children's toileting programs. While these issues must be addressed, they are often done so at the expense of more subtle problems like learning disabilities. It is much easier to ignore social and academic problems than continence ones. Unfortunately, the problems with adherence to toileting programs are often the result of children's learning disabilities and in the long term toileting problems may be minimised with intervention in the learning disability area.

The lack of available support

1. Because of the difficulties in obtaining sufficient and appropriate support for schooling, many parents and professionals look for a different label for their children, hoping to get more and better support. An unusual situation has recently arisen in Queensland whereby a number of children with hydrocephalus (not spina bifida) have received diagnoses of autism to attract support which is available for children with autism but not those with hydrocephalus.
2. It is inevitable that the quality of support provided depends to some extent on individual staff members. Factors such as experience with spina bifida and hydrocephalus, school culture, individual interest and motivation all play a part. However, the experience of SBH Queensland staff is that where support is not provided from outside the school, the level of support provided is very patchy and depends too much on individual teachers and school staff.
3. An additional system of assessing children with disabilities called profiling is being trialed in Queensland. This system promises to address the problems of individual children better, but because there are no extra funds for this program and the costs of the program must be met from within current funding levels, its introduction will mean that there will be less funds to provide support in the classroom.
4. Children with spina bifida and hydrocephalus who are ascertained for physical impairment level 1 – 3 (there are 6 levels of support) receive no support from outside the school. As those providing support from within the school often do not have a very good understanding of the complex issues of spina bifida and hydrocephalus, this support can be ineffective.
5. Both public and private education systems struggle to provide adequate levels of support for students. Often, funding for children with spina bifida ascertained for physical impairment from level 4 to level 6 is exhausted on issues of support with toileting and keyboarding. Funds are not available for help with access to buildings, movement between buildings etc. One of the results is that the children who need most class time are constantly late for classes.
6. The majority of children with spina bifida and hydrocephalus are in mainstream education, but many are directed to recommended schools, not local ones. The recommended schools are ones which are more accessible for children who use a wheelchair, or which have special classes or a special education unit for children with a disability. The parents' choice on where to send their children with spina bifida and hydrocephalus is swayed by the fact that children don't get taxi transport or resources at the local school. If parents wish to have these, then they must choose the recommended school.

The effect of increasing bureaucratic demands on SBH Queensland

1. There has been a trend for a number of years for teachers to be more and more involved with departmental issues. Because so much teacher time is now taken up with these issues, it is difficult

(sometimes impossible) to get teachers released from classroom duties to attend meetings about students in their classes with spina bifida and hydrocephalus or inservice programs on spina bifida and hydrocephalus provided by SBH Queensland staff. To meet this lack of availability of education staff, the number of inservices SBH Queensland provides to schools and the number of meetings attended by SBH Queensland staff has increased. However, this is not an efficient use of SBH Queensland resources.

2. In similar ways, the bureaucratic demands involved with assessing and providing programs to children are increasing. There is a greater emphasis on formal reports for the ascertainment process, which has skewed the work done by SBH Queensland staff away from direct support, information provision and consultancy.
3. SBH Queensland receives funding from Education Queensland and the Commonwealth Special Education Program. However, the level of funding covers just 84% of the costs of the program. This shortfall must be made up through fundraising efforts of SBH Queensland. This is quite a difficult task for a small organisation whose focus is on the provision of services to members.

Other issues

1. Children with spina bifida and hydrocephalus who have a lower socioeconomic background are at a significant double disadvantage. At school, these children, like others with a lower socioeconomic background, are at the end of the social pecking order. Their behaviour is often seen to be similar to other children from a lower socioeconomic background, which makes it harder to identify and therefore address the problems caused by spina bifida and hydrocephalus.
2. The children with spina bifida who do not have significant learning disabilities are often encouraged to go to a school with a Special Education Unit. These children can learn quite well in a mainstream classroom with a little support. There is still the perception held by many education staff that because a child has a disability they need a special program or special treatment. In these cases, not only do children receive inappropriate support, they are in an inappropriate learning environment.
3. Many teachers, school staff and early childhood education staff are unaware of the supports available. As a result many children do not receive the support which is available and which could help them at the time they are developing quickly and that support would probably be most beneficial.