

Educating a Child with Spina Bifida and/or Hydrocephalus

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SBH Queensland services to children

SBH Queensland employs ten staff (mostly part time) to work with 300 children throughout Queensland with SBH and their families. They cover the following disciplines:

- Occupational therapy 1.5 FTE
- Physiotherapy .9 FTE
- Speech and language pathology 1 FTE
- Education advisers 1.8 FTE
- Social workers 1.2 FTE

One of the Education Advisers (0.8 FTE is based in Townsville and covers North Queensland)

The services for children with spina bifida and hydrocephalus and their families include:

- Information and resources
- Family support and counselling
- Outreach trips to rural and regional Queensland
- Group programs such as: mobility and hydrotherapy programs
- Support through Children's Hospital Spinal Clinics
- Annual camp for 10—13 year olds
- Lending of aids and equipment for trial

The service for children is spread across 2 programs.

Service for children of school age (Education and Therapy Service)

The service for children of school age is partly funded by Education Queensland and is only for students who are verified. Education Queensland also partly funds SBH Queensland's Information Service. Funding for the Education and Therapy Service is supplemented with money raised by fundraising events and philanthropic grants.

Service for children below school age (Babies at Home Program)

The service for children and their families prior to starting formal education is not government funded and is wholly reliant on the support of philanthropic grants and fundraising events.

Spina Bifida and Hydrocephalus

What is spina bifida?

Spina bifida is the most frequently occurring permanently disabling birth defect. It affects the development of the spine and the brain (the central nervous system). It is a very complex impairment and most of the body's organ systems are affected. The amount of damage to the brain, spine and nervous system can vary considerably from person to person.

The effect of spina bifida on the spine is that at least one vertebra has only partly formed and the spinal cord at that point and below, as well as the skin around the site, have not developed properly. Spina bifida commonly occurs in the lumbar and sacral spine, where the nerves originate that control muscles and feeling in the lower limbs. Therefore, most people with spina bifida have some degree of paralysis and often need to use a wheelchair. Bladder and bowel function are also usually affected.

Visual impairment, epilepsy, headaches, orthopaedic problems of the spine and lower limbs, early onset of puberty, delayed fine and gross motor skills, and sleep apnoea are some other common effects of spina bifida. Children with spina bifida can have frequent and long absences from school while in hospital or at home recovering from medical procedures.

The effects of spina bifida on the brain present as improper development of many of the brain's structures. In about 90% of people with spina bifida this causes hydrocephalus.

What is hydrocephalus?

A clear liquid called cerebrospinal fluid (CSF) circulates throughout the brain cavities, called ventricles, over the surface of the brain and spinal cord, and is reabsorbed by the body. The CSF protects and nourishes the brain.

Hydrocephalus is the build-up of fluid and increased pressure on the brain resulting from a blockage to the flow of CSF through its natural pathways. If left untreated further damage to the brain will result. Hydrocephalus is usually controlled by a surgically implanted shunt; a one-way valve with two flexible tubes attached, which 'shunts' the excess CSF to the abdominal cavity.

Hydrocephalus will usually have been present throughout the foetal development of most children with spina bifida and this will have further affected their brain development.

As a result of both hydrocephalus and abnormal brain anatomy, most people with

spina bifida have cognitive problems sometimes termed 'learning disabilities'. Although the extent of the problems varies greatly from individual to individual there is a typical cognitive profile with particular strengths and weaknesses. The weaknesses in this cognitive profile are similar in many ways to executive dysfunction.

Children without spina bifida can also be born with hydrocephalus and it can also develop after birth from any condition which has an impact on the structure of the brain such as tumours or cysts. Children born with hydrocephalus but without spina bifida can also have similar cognitive problems.

Why does spina bifida and/or hydrocephalus cause cognitive challenges?

Quite simply put, the brain has been changed by other medical co-existing neurological factors associated with spina bifida and/or hydrocephalus. As educators, we see the **physical** implications of spina bifida, however the cognitive challenges are less obvious initially and can be quite challenging to cope with as curriculum expectations increase. Our knowledge of the brain has significantly increased with the invention of MRI's (Magnet Resonance Imaging) which takes pictures of the brain to see how it responds to events and images. There is still so much to be learned about the brain and in particular how it has been affected by neurological factors associated with spina bifida and hydrocephalus so much care has been taken to ensure current research is included in this booklet.

The main *neurological* reasons as to why the brain has been altered as a result of spina bifida and/or hydrocephalus include:

Arnold Chiari Malformation – Type II

As indicated by the picture below, the cerebellum is 'squashed' into the upper part of the spinal canal. Although the brain anomalies vary from person to person, almost everyone with spina bifida has the malformation. This anomaly is also believed to be the reason why most people with spina bifida are also born with hydrocephalus. In the past it was thought that the main implications of this malformation and subsequent damage to the cerebellum was to balance and coordination however new research indicates that the cerebellum also plays a role in executive functioning.



• Hydrocephalus with or without VP Shunting See above under "What is Hydrocephalus" for more information.

The cognitive implications of excess fluid build-up on a developing brain can vary depending upon when the complication started (pre birth or post birth), subsequent shunt surgeries to repair a malfunctioning shunt or whether an infection such as meningitis has occurred.



Spinal cord tethering

Virtually everyone with spina bifida has a tethered cord because of scar tissue damage at the site of the lesion. The spinal cord is meant to move freely up and down the spinal cord however if the *tethering* becomes symptomatic (the child experiences back or leg pain, loss of muscle function, deterioration in bladder and/or bowel function), it may be necessary to have an operation to 'detether' the spinal cord.

What are the main educational

implications as a result of the above conditions?

- 1. Executive Functioning
- 2. Language including the understanding and use, appropriateness of use and comprehension
- 3. Social Emotional Wellbeing.

(See Mind Map "Educational Needs in a Nutshell")



1. Executive Functioning

Research and experience tells us that although the impact of spina bifida and hydrocephalus is very individual, there are some common areas where many people with the neurological implications of spina bifida and or hydrocephalus struggle. One of the most common things we are asked about by both schools and families surround the areas of task initiation and motivation. These skills form part of our Executive Functioning and have a lot to do with what could be perceived by educators and parents as 'laziness' or 'lack of motivation' by the child. The frontal lobe of the brain controls executive functioning and "refer to the brain-based skills that are required for humans to execute or perform tasks." (Dawson, P & Guare R, Smart but Scattered p 13) Executive skills can be divided into two areas; cognition (working memory, planning/prioritization, organisation, time management and metacognition) and behaviour (response inhibition, emotional control, sustained attention, task initiation, goal-directed persistence and flexibility.) Research suggests that we all have the potential to develop Executive Skills from birth and that they lie dormant in the brain ready to be activated at a later stage. This activation only occurs if:

- Biology Everyone has the potential to develop the necessary executive skills however if these skills aren't modelled and explicitly taught, they may be delayed or not develop at all. The executive skills of the primary caregivers play an important role in this development.
- 2. Executive Functioning delays are identified and a programme is started to explicitly teach these skills.
- 3. The environment is free from trauma or abuse. If the environment is toxic or the child is experiencing trauma as a result of the disability, executive skills will be delayed. (see Mental Health and Wellbeing section for more)



The frontal lobes are considered to be the 'output' part of the brain and can be likened to that of a conductor of the brain's orchestra directing a coordinated approach of many players. If all the different parts of the frontal lobe do their job, the result will be beautiful music, however if some parts 'forget' their timing or do not organise their music sheets in the right order, output will be chaotic. Figure 2 looks at each executive skill separately and identifies how it is likely to present in the classroom. It is important to note that executive skills do not work in isolation from the rest of the brain's functions so identifying or assessing specific weakness can be difficult and needs to be done in context of the activity. An example of this would be if the student in grade 5 had to do a book review on James and the Giant Peach by Roald Dahl. There are many executive skills which need to be employed in order to complete this task.

First, the student needs to have the skills to *start* the task. In most cases, students with spina bifida and/or hydrocephalus are very functional readers so it may be a very achievable task for the capable reader, however reading and comprehending are two different abilities. The student would need a good understanding of language and have the ability to understand inferences made in the book.

Second, they have to use their **working memory** in order to link future chapters with chunks of information given in past chapters and they also have to understand what information is important in order to address the assessment task.

Third, the student will need to have a system for organising the information so they can address the assessment task in a logical manner. This is all before they even start writing the assignment. There are many other executive skills that need to be employed including staying on task until the assignment is finished (*task persistence*) and *time management* so the assignment is completed when required and not left to the last minute. Hopefully this brief analysis will show how delays in executive function can significantly affect a student's performance.

Executive Skill	Description	How difficulties	Strategies to
		classroom	improve weakness
Working memory	Memory is vital in the learning process. It involves the ability to retrieve meaningful information, hold and manipulate information mentally and link past learning to new information.	 Fails to complete tasks Difficulty following directions Incomplete response to oral questions Needs instructions repeated Struggles with mental maths Difficulty recalling plots, events character traits. 	 Information should be presented in sequential, step by step manner Link past learning with new learning Teach student strategies for remembering, such as writing important dates in diary and using scrap paper for working. Help student decide what important information is and what isn't by using highlighting pen. Use student's neuropsychological or OT assessments to determine realistic expectations.

Executive Skill	Description	How difficulties	Strategies to
		present in the	improve weakness
		classroom	
Organisation	The ability to organise your mind and your surrounding environment in an efficient manner.	 Has a messy desk and notebooks Can't find belongings when asked Difficulty producing a sequential written task 	 Explicitly teach this skill in the early grades and have specific expectations that the student keep environment tidy. Ensure handouts are put where instructed and allow student to use a folder for handouts rather than pasting into a book. Provide opportunities for student to 'think aloud' or talk through how they will proceed with a task. Ask student to evaluate their organisation skills Provide time to organise.
Time Management	This skill is closely linked to goal setting and planning. It is the ability to understand or have a 'sense' of time and estimate the amount of time required to complete tasks.	 Difficulty producing work on time. Underestimates how long a task will take; often leaving things to the last minute Misses deadlines. Arrives late to class 	 Provide visual representations of time such as clocks or countdown timers. Explicitly teach time in connection with daily/weekly schedules Work closely with parents so they are aware of deadlines Ask student to become a time monitor for classroom activities.
Goal Directed Persistence	The ability to identify goals and stick to a task until it is finished. This is closely linked to organisation as the student needs to see the 'big picture' but also determine the steps involved to get there.	 Stops working on tasks when they become too difficult Procrastinates by doing other more enjoyable tasks Doesn't understand the sense of achievement to finish a task Needs frequent teacher cues to keep on task Does not work well independently 	 Break tasks up into smaller chunks Try to incorporate student's interests into the topic to provide intrinsic motivation Provide 'check-in points' along the way to monitor progress Use mind mapping to help structure task.

Metacognition	The ability to self evaluate and self monitor how you are going in a situation. It also includes the ability to change direction if needed.	 Asks for help rather than trying to solve the problem independently Is unaware how others perceive or react to their behaviour Finds problem solving difficult Doesn't review or check answers before submitting work. 	 Use coaching sessions to ask the student how well they did on a task Use goal setting sessions to think of ways to overcome potential obstacles Explicitly teach the student to self evaluate to become a good learner
Flexibility	The ability to revise plans in the event of challenges without 'freezing' in the face of a setback. The ability to cope with change.	 Easily upset by a change in plans Doesn't adapt well to disruptions Finds it difficult to look at other ways around a problem Finds it difficult to move on to another project whilst not finished a previous task 	 Keep to schedules and routines where possible Provide advance notice when a routine will change Break tasks down so that the student doesn't get overwhelmed Role play situations you know will be difficult for the student
Sustained Attention	the capacity to keep paying attention to a situation or task in spite of distractions, fatigue or boredom	 Fails to complete tasks on time Has difficulty with reading comprehension activities Distracted by the environment around Rushes through or gives up quickly on tedious tasks Cannot recall information Difficulty following instructions 	 Gradually increase attention span by using a timer and providing breaks Where possible, provide supervision to help the student stay on task Use an incentive system to encourage work to be completed Use student's interests to keep motivation Give praise when the student is on task Give the student something to look forward to when task is finished.
Task Initiation	The ability to start a task without procrastination and the ability to complete tasks on time.	 Needs constant verbal cues to get started Waits for others to begin in group activities 	 Provide visual cues of time and task Ensure the student makes a plan to complete the task Break task into

Planning and Prioritisation	The ability to create a roadmap to reach a goal or to complete a task. It also involves the ability to decipher what is important information from what isn't	 Has difficulty carrying out a long term project in a logical order Has difficulty following a timeline Doesn't contribute in a meaningful way during group work Finds it difficult to decide what is meaningful info Gets bogged down in irrelevant details 	 manageable chunks Give rewards for starting task in a timely manner. Ensure the student understands the task Model planning by developing checklists and ensure the student sees the planning process. Take an active role in helping the student decide what the priorities are and gradually give the student more responsibility. Ask the student to verbalise what needs to be done first
Emotional Control	The ability to manage emotions to achieve goals, complete tasks, or control and direct behaviour	 Has frequent tantrums Overreacts to small problems Becomes overly anxious Slow to recover from disappointments May encounter social problems 	 Where possible, minimise stress that may lead to bad decisions. Develop a routine that is predictable Promote positive self talk by developing a script for the student to say in stressful times
Response Inhibition	The ability to think before you act and control impulsive behaviour. It also includes the ability to understand how the behaviour might impact on others	 Blurts out answer without raising hand Talks back Makes insensitive comments Can't wait while a parent/teacher is talking to someone else May get into trouble for retaliation. 	 Introduce the concept of 'first/then' to encourage work before play. Teach delayed gratification by using a visual timer Require the student to 'earn' things they want Establish rules and consequences which are understood Discuss required behaviour before they enter a situation and reward self control



Executive Function and Maths

When you look at the above executive skills and how the difficulties present, it is no wonder the many students with spina bifida and/or hydrocephalus find maths incredibly difficult. When you add the language difficulties (to be discussed later) in addition to the handwriting difficulties we often see students label themselves as poor at maths by grade 4.

Having said that, we do see some relative strengths in early maths ability including single digit addition, subtraction and multiplication because these skills can be rote learnt and automatic which means that it relies less on the executive skills of the student. The problems start when the student has to take a basic concept and use it to solve multi-step equations. These issues are further enhanced when students have time limits and have to use estimation as an initial step to solving the problem.

2. Language and Communication

Language skills, in particular comprehension (understanding of language) and expression (production of language) are incredibly important for learning in the classroom. There are many rules that govern the use of language which can be very difficult to understand. Research shows that from Prep to year 3/4, students with spina bifida and hydrocephalus show good language skills, verbal expression and progress nicely with sight words. (Dise & Lohr, 1998) However when you look at the Learning Continuum from year 5 onwards, there becomes a need to have a deeper understanding of how language is used to get meaning across.

At times, the language difficulties can be masked by adequate expressive language that most children with spina bifida and/or hydrocephalus have, but it is not until the draft/worksheet has been completed that it becomes obvious the student has misunderstood the task at hand. In fact, many students we support at SBH Qld have excellent reading skills which further mask the problems with language, but *reading* and *comprehending* are two very different skills. It is also important to remember that if a student struggles to read, they will be putting most of their effort into reading the words on the page and not into understanding what the words are saying.

The main language difficulties that are commonly seen amongst children with spina bifida and/or hydrocephalus are:

- difficulty with comprehension
- difficulty with keeping to the topic (with school work and conversations)
- difficulty with word retrieval
- difficulty with auditory recall and processing of information
- difficulty with high level language skills (e.g., inferencing, understanding jokes, indirect requests, figurative language, idioms, poems, and sarcasm)
- difficulty with picking up on non-verbal language (e.g., body language, facial expressions etc)
- difficulty with social aspects of language (e.g., following the rules of conversation, topic maintenance, conversation repair, personal space etc)
- difficulty with identifying the main idea/points in a passage of information

Research consistently shows that children with SBH generally have a low average IQ level. However as they progress in years at school, this potential is not mirrored in achievement levels on their report card or in their ability to become an active member or the workforce after school. Problems with both language and executive skills are the main reasons for this so it is up to all of us to assist the student with spina bifida and/or hydrocephalus to reach their potential.

Some of the positive ways an educator can help a student through these difficulties include:

- ✓ allow the student to make notes 'along the way' by highlighting or typing notes up for a comprehension activity. Some schools are loading relevant texts onto a portable tablet device as they are restricted by copyright laws that limit photocopying. This allows the student to highlight text as they go along.
- ✓ When doing sequencing activities, allow the student to highlight 'clue' words, such as first, then, next. This makes finding the relevant text to answer the questions easier.
- Allow the student to read the questions first so they have some inkling of what they are looking for as they go along.
- Students may benefit from using ipad apps such as IThoughts which use mind mapping techniques as a way to organise their thoughts before starting their assessment.
- Does handwriting affect a student's performance? Most teachers use templates as a way for students to break down project tasks under headings, (eg Characters, plot, summarise chapter etc), however if they can't read their writing when they go to do their first draft, this can be frustrating.
- Is it possible to differentiate the content so that the student's interest is catered for rather than reading material stated in the planning?

Contributions to this section made by Amber Katavic – SBH Qld, Speech and Language Pathologist

3. Social Emotional Wellbeing

All learning comes from our senses. We *hear* information, we see *information*, we can use concrete materials to *feel information*, and so on. Early in this booklet we reported that Executive Skills only develop if the parents/guardians have the skills themselves and if the child is not in an environment with trauma and abuse. There is much research now that defines what trauma and abuse encompasses and it is suggested that having a disability such as spina bifida and/or hydrocephalus can be a significant trauma on the family structure and the individual. When we have ongoing trauma or stress in our lives, information that we usually gather from our senses fails to get to the prefrontal cortex (the part of the brain responsible for executive function), instead getting routed by the *amygdala* (located in the temporal lobe of the brain and an essential component in memory and emotion). This leads to a complicated knock on effect where the body goes in 'fight, flight, or freeze' mode and the information is lost. Children are more likely to learn when stress is low and learning experiences are relevant to the student.

David Sousa (2006) author of "How the Brain Learns" lists facts about the brain which impact on learning and includes the following comments:

Survival and emotional data have higher priority for processing than learning concept-based curriculum. (Therefore) Students must feel physically safe and emotionally secure before they can focus on cognitive lesson objectives;
The self-concept has great influence over whether a person will get involved in a particular learning experience. Not surprisingly, individuals tend to participate in learning activities that result in success and avoid those that end in failures;

There may be a primary physical (physiological) basis for difficulties in learning as well as a secondary cause. Lack of confidence, trauma and mental health can also impact on learning these skills.

Physical contributors

Primary:	Physiological	Pressure on the brain Different anatomy of the brain Neurological input to the brain Trauma from the condition
Secondary:	Experiential	Trauma from medical intervention Extended time unwell or in hospital Difficulty getting about and exploring Limited experiential learning Impact on stages of development

Emotional (mental health) contributors

Primary	Impact of slow processing (not being able to keep up) Impact of being unable to achieve what the body wants to do (frustration) Impact of trauma
Secondary	Impact of observing difference from others of the same age Impact of being left out Impact of negative feedback from family, peers, teachers Low self esteem and self confidence
	Anxiety and depression

Secondary trauma may manifest itself as learning difficulties and slow processing as well as behaviour difficulties such as inattention and lack of motivation

Teachers and school staff are able to influence in a positive way the impact of these complex conditions on students learning:

- By looking beyond the obvious (presentation and behavior)
- By gaining an understanding of the condition and its impact for your student
- By gaining an understanding of the impact of (trauma) on learning
- By becoming aware of secondary emotional difficulties that mask and inhibit learning.
- By putting in place conditions that are conducive to learning for your student.
- By aiming to provide students with SBH the same every day experiences as other students as these experiences are the foundations for learning.

Contributions to this section made by Joan Abbott – SBH Qld, Social Worker.

Additional Information on Policies for Students with Disability



With the commencement of the National Curriculum and the many different resources available to schools (such as the C2C unit plans) there has been much confusion regarding differentiating the curriculum, how to use focused teaching with identified students, when an Individual Curriculum Plan is needed and how this fits with assessment and reporting for students with a disability.

The Disability Discrimination Act has been the major stepping stone for people with a disability to be treated fairly and 'on the same basis' as the rest of the community. It has also led to the development of policies such as Disability Standards for Education (2005) which requires educators to make reasonable adjustments to the curriculum and their teaching of the curriculum in order for students not to be disadvantaged by their disability.

The confusion lies in determining how much adjustment is necessary, how the student's current level is determined and how this impacts on assessment and reporting. Curriculum provision to students with disability – Policy Statement states that the "*majority of students with disability can access the required curriculum and achievement standards for their year level/age cohort.....with reasonable adjustments to teaching, learning and assessment.* (p2)

This would indeed be true for some students with spina bifida and/or hydrocephalus especially in the first few years of education. However as discussed earlier, many students with spina bifida and/or hydrocephalus start to struggle with curriculum expectations around year 4/5 and may therefore require a negotiated Individual Curriculum Plan.

It is very difficult to know exactly where a student's general capabilities fall within the Learning Continua however a meeting with all the support team (including parents/guardians and a member of the Admin team) will be a good starting point. Use of the year level achievement standard will help the team to identify the appropriate year level curriculum to be taught.

An example of this process would be to look at the Literacy Learning Continuum in General Capabilities. By the end of year 6 (level 4) a student would be expected to use their developed language skills to interpret and analyse text, compare like texts and use developed comprehension skills to make inferences.

A student with spina bifida and/or hydrocephalus may be able to read and make some '*obvious*' inferences and have some basic comprehension skills but would struggle with the higher order language abilities needed to be successful at a Level 4. They may achieve more success at a Level 3 with some focused and/or intensive teaching with some structured scaffolding to the way the content is presented.

If the support team feels that the student will need a negotiated Individual Curriculum Plan in order to stay engaged in the learning process, the student will then be assessed and reported at the same level deemed appropriate on the learning continuum. For more information in this area go to http://www.australiancurriculum.edu.au/studentdiversity/students-with-disability

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