Spina Bifida Hydrocephalus Queensland

Early Childhood

Learning Strategies

Social Skills Development

Inclusion & Participation

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June 2013

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DISCLAIMER

This booklet is designed to provide general information about the topics covered to assist interested parties. It is compiled from information written by staff of the Association, as well as from various publications by authors not related to the Association. Accordingly, whilst the Association believes the information is the most accurate and up-to-date available, the Association accepts no responsibility for the information from other sources. There is still much to be learnt about spina bifida, including spina bifida occulta, and their causes and prevention. As further developments occur, the information may prove to be incorrect or incomplete. For this reason, and because the information is of a general nature, you should always obtain specific advice about matters affecting you.

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 spinal cord and also alters the development of the brain. It is a complex impairment and many other body organ systems are affected.

With spina bifida at least one spinal vertebra is only partly formed and the spinal cord at that point and below, as well as the skin around the site, is not properly developed. The amount of damage to the spinal cord and nervous system varies from person to person. 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 may also be affected. Additionally, the alteration to the brain's development causes hydrocephalus in about 90% of people with spina bifida.

What is hydrocephalus?
A clear liquid called cerebrospinal fluid (CSF) surrounds the brain and spinal cord to protect and nourish it. It circulates throughout the brain cavities, called ventricles, over the surface of the brain and spinal cord, and is reabsorbed by the body.

Hydrocephalus results from a blockage to the natural flow of CSF through its natural pathways. The blockage causes a build-up of fluid and increased pressure on the brain. If allowed to continue, nerve damage to areas of the brain will result. Because hydrocephalus has acted on the brains of most children with spina bifida since early pregnancy, their brain development is almost always affected. Hydrocephalus can occur in children without spina bifida, and can develop after birth.

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. Most people with hydrocephalus from birth have cognitive problems often termed 'learning disabilities'. Visual impairment, epilepsy, headaches, early onset of puberty, delayed fine and gross motor skills, and sleep apnoea are some other common effects.

In this booklet…

The Early Childhood booklet seeks to provide early childhood teachers, as well as parents, with strategies that SBH Queensland staff have found useful in addressing some of the difficulties faced by children with spina bifida and/or hydrocephalus in early childhood.

For more information specific to your child or student, please contact SBH Queensland, the organisation that supports people with Spina Bifida and Hydrocephalus in Queensland (Ph: 07 3844 4600).

Early Childhood Learning Strategies for the Child with Spina Bifida and/or Hydrocephalus

During the before school years children compile a tremendous amount of learning. The skills and abilities they develop in these early years form the basis for more complex activities, such as reading and writing. Entering formal schooling at about age five presents higher expectations, such as sitting still and following more complex directions. Children with spina bifida and/or hydrocephalus have often spent significant amounts of their infancy and early childhood in hospital, and may have missed out on opportunities to develop the skills required for school. Their disability may also make learning more difficult, due to a slower processing speed or physically being unable to access the same opportunities as their peers.

It is important to remember each child is unique. Spina bifida & hydrocephalus affect each child differently.

Children with spina bifida and hydrocephalus will learn and benefit from regular activities already presented during a typical day at the childcare centre, kindergarten or school. The following ideas and strategies are helpful in the learning process of all children but especially important to include when working with children with learning difficulties.

Teaching the child with spina bifida and hydrocephalus at a developmentally appropriate level will ensure he or she has the best opportunity to progress at the same rate as other children their age. For more helpful information or strategies, contact the Education and Therapy Service (ETS) at SBH Queensland. ETS is a team of experienced professionals, including education advisers, physiotherapists, a speech pathologist, occupational therapists, and social workers, who work in partnership with schools, families, and hospitals.

Visual Perception & Visual Memory

Ability to recognise, understand and recall what is seen

Strategies:

- Memory games
- Sorting games
- Jigsaw puzzles
- Games with shapes, cutting out, tracing
- Put various items on a tray, let children see, cover and ask children to name items
- "What's missing" game
- Matching games: dominoes, spot-the-difference, matching card games
- Snapshot: present child with photo of item in room. Remove photo and ask child to find same item in room.

Perceptual Motor Skills

These skills are vital for learning handwriting and other fine motor skills, as they provide pathways for eye-hand coordination and adjusting movement in response to visual feedback

Strategies:

- Jigsaw puzzles
- Threading beads/pasta/spools
- Weaving wool through a plastic grid (e.g. gutter guard)
- Mazes and dot-to-dots
- Colouring in
- Blocks, Duplo, Lego

Spatial Awareness

Understanding concepts like up and down, in and out, in front and behind. Judging direction and distance between two objects, object and self.

Strategies:

- Use directional language to encourage children through an obstacle course, e.g. “into the tunnel”, “left of the pole”.
- Music sessions: exercises in class, movement with instructions e.g. “turn around”, hokey pokey, following set actions
- Folding paper aeroplanes or simple origami
- Finding hidden objects using the “hotter / colder” game

Auditory Perception & Auditory Memory

Listening to and remembering auditory input in order to form a response, e.g. listening to verbal instructions and keeping each step in mind to be able to carry out the instructions

Strategies:

- What's in the bag: listen to items in a bag
- Name calling: when you hear your name, go to the table
- Ask questions about a story just read to children
- Learning songs and rhymes
- Repeat claps
- Number instructions, e.g. "1 – get your hat, 2 – get your drink bottle, 3 – line up at the door"
- Child to repeat back key words from each step, e.g. "1 – hat, 2 – drink bottle, 3 – line up"
- Make instructions multisensory by using gestures or pictures as well as words
- Simon Says

Attention and Concentration

Many factors affect how much attention a child will give to an activity, such as the child's level of interest, motivation, proficiency, and distractions in the environment around them. As children develop, they are able to maintain attention on a single task for longer periods.

Strategies:

- Give complex activities in smaller chunks
- Break multi-step instructions down by giving 1-2 steps at a time
- Give set time-frames that children are expected to concentrate for on activities they find challenging or uninteresting, and provide a visual cue (e.g. egg timer, hour glass, analogue clock)
- Structure activities to provide opportunities for whole-body movement between sitting activities, and transitional activities/routines to focus attention upon return to the classroom from outdoor play
- Children with difficulty concentrating should be placed at the front, near the teacher to avoid distraction from other children
- Limit distractions in the environment as much as possible, e.g. people moving about the room, lively music or loud background noise

Memory & Learning

There are many different types of memory, including long term memory (last year's holiday to the beach), short term memory (what happened earlier today) and working memory (remembering the character's names in the story I'm listening to, or holding numbers in mind for mental arithmetic). For memory to be transferred from working memory to long term memory, it has to be encoded and recalled.

Strategies:

- Multiple repetitions, rote learning
- Memory games with flash cards
- Make use of all the senses when introducing new information (e.g., pictures, videos, talking, listening, rhymes, songs, performing actions, constructing something, touching, tasting, smelling)
- Preteaching: before introducing a new topic, remind children of things they have previously learnt that provide links for context

Organisation

Organisational skills include management of physical resources (such as hat, lunch box), time management, and self management (such as being in the right place, at the right time).

Strategies:

- Develop consistent routines
- Introduce a daily or weekly visual schedule, with pictures to represent different activities
- Introduce a certain ritual for transition such as pack-up song, clap, bell etc.
- Give notice before changing activities
- Introduce "choice chart" to help children learn to organise free time. At group time children are given their symbol or name to stick on a chart. The child selects one activity at a time.
- Extra prompts may be required to help the child stay organised

Handwriting

Developing fluent handwriting incorporates a range of complex skills, including fine muscle control, visual motor integration, visual and motor memory, upper limb and sitting stability, spelling, working memory, and proprioception. Developmentally, children are usually ready to formally learn to write after age 5.

Strategies:

- Painting with fingers, stamps and paint brushes, on horizontal and vertical surfaces
- Modelling: clay, play dough etc.
- Construction: Duplo, Lego, scissors & glue, paddlepop sticks, etc.
- Drawing with short crayons or chalk
- Encourage drawing a variety of shapes (circles, triangles, squares, rectangles...) and line styles (wavy, straight, zig-zag, continuous 'e'...) before mastering letters
- Start with teaching the child to recognise the letters from their own first name, then to write the letters

Sensory Modulation

During early years of development, children discover the look, feel, taste, smell, and sound of different objects and experiences. During this phase of intense exploration, the brain learns what's 'normal' and what's dangerous or different. It creates a filter so that if anything is detected that is dangerous or different, it will be immediately recognised, but 'normal' things are ignored. For example, a hand resting on a wooden table is normal, so minimal attention is given to how the table feels, but a hand resting on something prickly is different, so attention is drawn to the discomfort to allow the person to respond by moving their hand. For each person, the sensory filter works slightly different depending on experiences, preferences, and personality.

For some children, the filter develops significantly differently and is under-active (so they respond to stimuli most people would consider 'normal' and ignore, like the sound of the air conditioning) or over-active (so things get filtered out that they really should be paying attention to, like not removing warm clothing on a hot day). This can cause difficulties with attention and concentration, participation in activities that involve textures they may be sensitive to, food texture aversions, and other day-to-day functions.

Occupational Therapists at SBH Queensland are trained in assessing sensory modulation difficulties and can provide strategies specific to the child.

Social Skill Development in the Preschool Child with Spina Bifida and or Hydrocephalus

Beginning in kindergarten and developing into Grade 2, children will move from playing by themselves, or next to peers, to playing in small groups. During these years children learn to take turns, cooperate and share. They become more aware of individuals in their class. They begin to acquire "best friends." They also develop self-advocacy skills, including asking questions, nagging teachers and arguing. Children with spina bifida and/or hydrocephalus may show delay in any of these areas because of limited mobility, lack of experience, learning difficulties, or other factors related to their disability.

Adult Interaction

Children with disabilities often receive an increased amount of adult interaction compared to their peers. Some extra contact is unavoidable, such as when in hospital or when they need help with activities of daily living that other children may perform independently (e.g. toileting). Due to spending more time with adults than other children, children with disabilities may develop conversational skills for interacting with adults, but may have difficulty interacting socially with children of the same age.

Strategies:

- Redirect children to play with peers if they consistently seek out adults
- Plan activities for pairs or small groups of children
    - water play
    - painting together on large sheet
    - board games
    - home corner, dramatic play
    - building blocks, construction area

Patterns of Social Engagement

Most people learn social skills automatically by seeing, copying and conditioning, often without noticing. People develop different patterns of behaviour to suit different situations, e.g. behaviour is different when at home compared to when interviewing for a new job. Children with spina bifida and/or hydrocephalus may have learning difficulties that make it difficult for them to learn what's appropriate and inappropriate for different situations without being taught.
Difficulty understanding appropriate patterns of social engagement can cause serious problems. Children with hydrocephalus often have difficulties with:

- Judging personal space and public vs. private
- Understanding the meaning behind the tone of voice used by other people
- Non-verbal cues such as posture and facial expression
- Understanding other people's points of view, turn taking, choosing topics of mutual interest, and repairing misunderstandings.

The acquisition of social skills early is critical for social inclusion. These skills can be broken down into component parts and taught like other skills. The preschool curriculum includes many opportunities for learning social skills and these should be seen as a high priority to avoid social isolation and low self-esteem. For children who don't automatically pick up social skills, rules for social behaviour need to be taught and continually reinforced. It is important for teachers to:

- Set clear and consistent expectations
- Ensure that *all* children understand the social behaviour rules set by teacher
- Monitor social interactions between children and tailor teaching social skills to the needs of the group
- Consider teaching about conversation (listening, taking turns, asking questions), play (sharing, cooperation, helping), personal space

Careful planning, programming and implementation in settings prior to school will enhance all children's learning of these skills. The teacher's role is that of facilitator and model, and when the children become more adept intervention can be faded.

Including and Maximising Participation of your Student with Spina Bifida and/or Hydrocephalus

Children with disabilities, such as spina bifida and hydrocephalus, often stand out from the crowd due to their physical, behavioural, or cognitive differences. Classrooms that successfully include students with disabilities are designed to welcome diversity and to address the individual needs of all students, whether they have disabilities or not.

Before assuming a child can't do something: ASK!
The child may also be able to tell you how they have participated in the past.

Attitudes

The attitude you portray to the children in your class about disability has a significant impact. The words and actions you choose say a great deal about your feelings towards people with disabilities, and are easily internalised and imitated by young children. If staff are welcoming of diversity, exclusion or bullying is less likely to be an issue.

Strategies:

- Treat children with disabilities the same as other children, as much as possible. Provide only as much assistance as is required to support the child performing to their full potential. Avoid babying.
- Be careful to use inclusive, person-first language. See the guide "A Way with Words" by the Queensland Government Department of Communities, online or in print
- Don't put children with disabilities on a pedestal, being overly euphemistic can be as damaging as being derogatory.

Physical Inclusion

It is important that the environment is appropriately set-up to support independence. Modifications may be required, e.g. installation of a wheelchair ramp, adaptations to toilet facilities, or changing desk height, depending on the student's individual requirements. Alternative seating may need to be considered for floor time, and alternative mobility for outdoor play to enable the child to be involved. A physiotherapy or occupational therapy assessment may be of benefit if the child is facing barriers to participating to the same extent as his or her classmates.

With a little creativity, most activities can be modified to include everyone. The rules or expectations may need adjusting, or the game could be played somewhere different, such as playing ballgames on a hard floor surface rather than grass so that children who

use wheelchairs can participate. In modifying activities, try not to single out children with disabilities, but rather change the rules for everyone and try to keep the group together.

While games and activities should be made achievable for the student who has spina bifida and/or hydrocephalus, they shouldn't be too easy either. Motivation is present when an activity is purposeful and achievable. If too hard, or too easy interest and motivation will be lacking. To make the child motivated, we need to set achievable goals and build up self-esteem.

Social Inclusion

Research shows that when people know more about why someone is different (e.g. their disability), they are less likely to tease or bully the person for his or her difference, and more likely to treat the person positively.

Strategies:

- Awareness program: Read story about child with disability. To avoid singling out the child with spina bifida and/or hydrocephalus choose another disability first.
- Introduce a personal talk time: A time set aside each week that is open for discussion on a variety of issues relating to socialisation, feelings, attitudes and behaviour. For example, start with senses "what would we do without sight?"
- Involve students to think of a way to change a game so that the child with the disability can participate
- Include a wide variety of games into your program so that everyone has an opportunity to show off their talents
- Contact the child's parents or SBH Queensland for more information specific to the student in your class with spina bifida and/or hydrocephalus. SBH Qld staff are available to conduct in-services to staff and class presentations

We hope this booklet has provided useful strategies to promote healthy development and integration into your educational setting for your student with spina bifida and hydrocephalus. If you have further questions, please don't hesitate to contact the Education and Therapy Service (ETS) at SBH Queensland, phone 3844 4600.

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