

UNDERSTANDING EXECUTIVE FUNCTIONING ISSUES IN PEOPLE LIVING WITH SPINA BIFIDA

WORKSHOP FACILITATED BY
DR CAROLYN WEST AM

Executive Functioning

- Executive functioning is always affected in patients with hydrocephalus even when shunting is not required
- Specific deficits and extent of deficits varies from patient to patient
- Executive functioning – organising and planning, problem solving, motivation, multiskilling
- Last to develop, first to be lost

Preschool Child

- Encourage age appropriate skills – fascilitate rather than “do”
- Encourage thinking - extend sentences eg
What happened next?
- Enable simple choices
- Preschool is excellent preparation for school – should be strongly recommended

School Aged Child

- Structured day, regular routines
- Didactic teaching, lots of repetition, revision
- Concrete reinforcement
- Prepare for the day
- Anticipate change
- May need to assist with socialisation

Examples

- 7 year old child is reluctant to go to school one day. Mother cross , child procrastinating
- On discussion child reveals her teacher will not be at school that day
- Child anxious about change and what will be expected of her
- What would you do to address this situation?

In the Classroom

- Structured Learning
- Reduce stimulus/business of classroom
- Reduce distractions
- Simplify the tasks into steps
- Make sure child understands the task
- May need help to begin, organise the task
- Memory – need to store information in an organised fashion

Examinations

- Disadvantaged in exam situation
- May have difficulty understanding question
- Organising/planning slower
- Writing slower
- Time restraint – often do not complete exam
- Anxiety makes all these issues worse
- Role of multiple choice
- What special provisions are helpful?

Post school skills training

- Plan well ahead
- What ABILITIES does this young person have?
- What limitations does this young person have?
- What are the person's interests?
- What are the local resources?
- Draw up a short list of options, discuss with child, explore opportunities
- SUPPORT in transition from school to skills training

Job Agencies

- Role of Specialist job agencies
- When to use them?
- How do they learn about the special needs of people with Spina Bifida?
- What information is available to them? – school reports, medical information, personal information, neuropsychological reports
- What type of work suits this group? What does not suit this group?

Issues in the workplace – Initial Employment

- Transport and parking
- Physical environment - work station, access, lift, toilets
- Time management, suitable work and expectations
- Supervisor/team work/job agency support
- Compatibility with others at work
- Role of part time work

Employment issues after initial period

- Building on skills slowly
- Being on time, time management in job
- Staying healthy
- New tasks – please show me how you like this work done
- Recognising stress at work and seeking help
- Maintaining good relations in the work place

Some Examples

- 35yr old lady with SB – she has mobility issues walks with AFOs and crutches, has incontinence managed on CIC, lives completely independently, drives a car
- Worked in a group home for people with intellectual disability for 10yrs –loved her job
- Job became too physically challenging for her.
- Changed to a desk job with an airline company

Example 1 cont

- Going well, making bookings for routine customers based on paper/email requests
- Given promotion with better pay. Now expected to take phone requests, urgent bookings, frequent flyer discounts etc
- She became very stressed, very anxious – rang me for appointment
- What is going on here? How can she be helped?

Example 2

- 23yr old man. SB, limited mobility, uses AFO's crutches, incontinent, shunt for HC
- Completed HSC at comprehensive high school
- Completed TAFE course in welfare.
- Enrolled at University to do social work, completed first 2yrs. In 3rd yr needed to do practical placements. Placement in busy SW dept of a Sydney hospital was too much – why? What can we do to help?

Example 3

- Two young people with SB develop a friendship become engaged. What are the issues?
- Realistic expectations
- Practical issues re physical abilities
- Problem solving re accommodation/running a household
- Budgeting
- Planning a wedding
- Expectations re marriage/family/ living and supporting one another

Example 4

- 40yr old man , SB, mobile in Wheelchair, incontinent. Lives with his wife and 2 children
- Long term job with bank
- Bank offering redundancies because of economic downturn
- Offered promotion or redundancy - tried new job – much more multiskilling
- What are the issues here? How can we help?