

Students with shunted hydrocephalus and spina bifida in 5 Australian schools



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Hallmark signs of an NLD

Strengths:

- Verbal skills
- Repetitive motor tasks
- Rote memory
- Simple concrete maths

Weaknesses:

- Short-term memory
- Motor coordination
- Problem-solving, decision-making
- Planning, organisation, time management
- Handling new tasks & situations
- Understanding social interaction



○ Persons at Level 1 risk of an NLD?

Hydrocephalus (early shunted)

Callosal agenesis

Asperger syndrome

Williams syndrome

Turner syndrome

Velocardiofacial syndrome

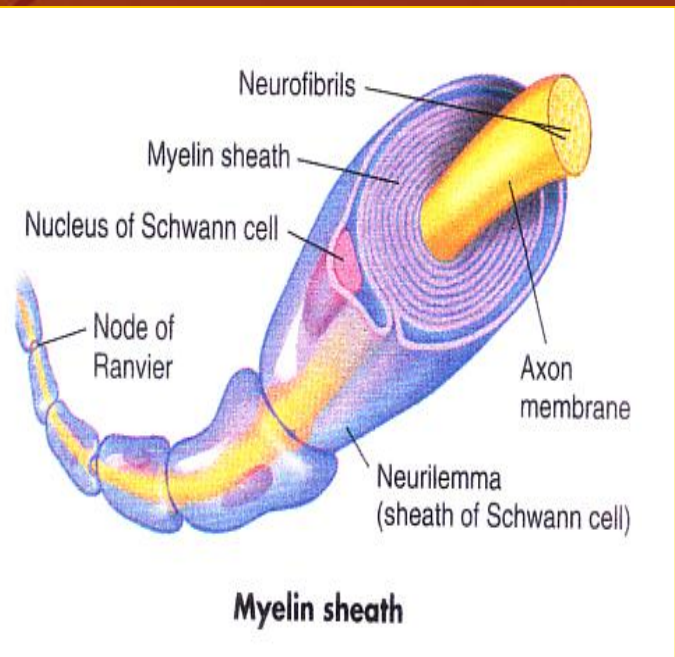
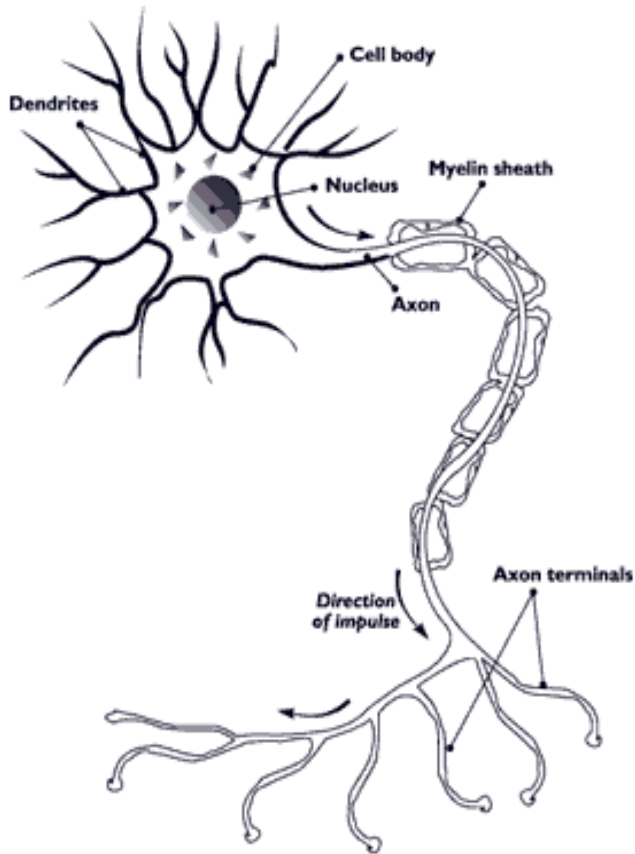
De Lange syndrome (Rourke et al., 2002)



○ How is hydrocephalus linked to NLD?

Rourke and others found that damage or destruction of right hemisphere white matter is the “final common pathway” that links hydrocephalus to the NLD syndrome (Rourke & Del Dotto, 1994, p.37)

How does this happen?



http://teens.drugabuse.gov/mom/tg_nerves.asp

Eynon T., Knighten D., Kruse Carolyn, Lee Matt., Downing, J. M., & Sparks, L. (Eds.). 2002, p.1140

Selection criteria

Aged 9-16 years in mainstream school

Shunted hydrocephalus related to spina bifida

Speak and read well (as perceived by parent)

Trouble with maths and handwriting

Live in Southern Queensland

Preliminary 15-question telephone interview ...



Data collection

43 interviews conducted with:

- 19 teachers
- 6 teacher aides
- 11 parents
- 2 grandparents
- 5 students

Psychometric testing conducted after interviewing

What I found

○ Case studies confirm literature reports about NLD in students with HC/SB

○ Psychometric testing confirmed different levels of severity

All students found to be severely learning disabled

All high on NLD parameter

All students had an Executive Function (EF) disorder

Parent reports of past school experiences

Families want effects of hydrocephalus ...

“Education System doesn’t understand ...”

“Education system doesn’t recognise ...”

One parent said: “The literature’s there ...

No formal help for teachers ...”

To get help, teachers had to ...

More training is needed ...

Apparent non-recognition by officialdom ...



Teacher perceptions of problems



“Well spina bifida’s meant she’s...”

“What do you do if the traditional instruction ...”

One student got “quite a few detentions” ...

Student who couldn’t work without aide ...

A student who couldn’t do things ...

“We’ve been told there’s nothing wrong ...”

Did teachers, parents, students know about NLD?

Out of 25 teacher and aides, only 1 teacher had read about NLD.

3 parents had heard of the NLD syndrome, 3 had not.

No students had heard of NLD but all wanted to know about it.



Teachers and aides said:

“Oh okay! That’s interesting ...”

“Ryan certainly has what you were saying ...”


“Nonverbal, what is it ...”

“I can see a pattern when she did test papers ...”

“Well I think that would be quite accurate ...”

Teachers and aides interested to “know what’s out there ...”

Strengths



Auditory perception

Well practiced
motor tasks

Rote memory

Concrete maths

Strengths

Parent and teacher perceptions

Good auditory perception leads to verbal fluency, good vocabulary and accurate pronunciation *and* good verbal skills enhance oral presentations, drama and speech delivery

Language assessment found there was much in their world the student did not comprehend fully and there was much in communicating ideas that the child found difficult. Language was 2-7 years below each child's chronological age.

Strengths

Parent and teacher perceptions

Simple motor tasks: dressing, undressing, personal care

Good rote memory: spelling, drama scripts

Concrete maths: simple addition



Weaknesses explained

Visual perception allows us to recognize and remember what we see

Visual and tactile perception are needed to look and feel for ...

Visual-motor perception needed to guide speed and manipulate ...

Visual-spatial-organizational perception needed to display work ...

Complex psychomotor skills refers to the mental ...



How teachers and aides perceived weaknesses

Visual and tactile tasks

Visual-motor tasks

Visual-spatial-organizational tasks

Complex psychomotor

Testing revealed all students had significant visual-motor & visual spatial impairments

Weaknesses explained

Planning & organisation: envisage, arrange ...

Time management: abstract, intangible concept ...

Problem-solving ability: need to visualize ...

Decision-making ability: need to hypothesize ...



Teacher, aide, parent perceptions of weaknesses

Planning and organization

Time management

Problem-solving maths

Decision-making

On the test of problem-solving ability, each child's age equivalent was 3-7 years below their chronological age.

Loneliness, friendships
Teacher, aide, parent perceptions

Loneliness and friendships

General help for school staff

Ensure all school staff aware of physical disability and shunt

With permission from family and student:

- Ask Principal to hang photo of student ...

Ask class teachers/aides to read student's file ...

Ask teachers and aides to discuss difficulties ...

Ask aide to take student on tour of new primary or secondary

If child has shunt, trouble with simple everyday tasks ...

Go to <http://www.nldontheweb.org>



General help for teachers and aides

Keep checking on students. “You can’t assume ...”

A pain scale may be useful ...

Explain the reality of school-day mornings

Advise how hard family works to increase independence

Offer neuropsych test results

Ask if school can modify some sport ...



Help in class



Tasks, assignments

Handwriting

Filling in missing words

Copying from board

Problem-solving maths

Finding stuff in desk

Social and friendships

Help with social interaction

Talk about any new task

Try to keep base of familiarity

Have open class discussions

Find talk time

Teachers positively encourage friendship

Role-plays can help

q  Ask aide to monitor group work

Be aware of this child in playground



Conclusion

Teachers need to be aware ...

Early identification ...

Teachers didn't conceptualize functionality ...

Educators need to realise that problems with organisation ...

Any combination of problems will profoundly ...

The immediate short-term effects of failure through school may be minimal
“compared to the durable impacts of their misinterpretation”

(Levine, 1994, p.272).

Further reading

Thesis: “They didn’t ask the question: Inquiry into the learning experiences of students with shunted hydrocephalus and spina bifida”
<http://eprints.qut.edu.au/16528/>

Journal article: “Nonverbal Learning Disability: The link to shunted hydrocephalus”
<http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3156.2010.00652.x/abstract>

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Psychometric test results

Mel	Josie	Ryan	Jenny	Clair
<ul style="list-style-type: none"> · SB and HC · Borderline Intellectual Impairment · Significant V-P discrepancy · full NLD · EF · Slow information processing · Severely impaired adaptive living skills 	<ul style="list-style-type: none"> · SB and HC · Borderline Intellectual Impairment · full NLD · EF · Slow information processing · Severely impaired learning and memory · Severely impaired adaptive living skills 	<ul style="list-style-type: none"> · SB and HC · Low average intelligence · Partial NLD · EF · Slow information processing · Specific memory Problems · Severely impaired adaptive living skills 	<ul style="list-style-type: none"> · SB and HC · Low average Intelligence · Significant P>V discrepancy · Partial NLD · EF · Specific language disorder · Difficulty with most areas of daily living 	<ul style="list-style-type: none"> · SB and HC · Intellectual Impairment · Severe difficulties in all areas of learning · Partial NLD · EF · Severely impaired adaptive living skills

SB spina bifida
 HC hydrocephalus
 V-P verbal-performance

NLD Nonverbal Learning Disability
 EF Executive Function disorder



Thank you