

ORIGINAL ARTICLE

Nonverbal Learning Disability explained: the link to shunted hydrocephalus

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Accessible summary

- Children with a Nonverbal Learning Disability (NLD) resulting from shunted hydrocephalus and spina bifida face many difficulties not experienced by those with a language learning disability.
- As they grow older and more autonomy is expected, friendships became harder to sustain and daily life can be full of fear if the nonverbal learning disability is not identified and managed.
- This paper explains the theorised cause of nonverbal learning disability damage to right hemisphere white matter or myelin.
- Damage is believed to cause problems with planning, organisation, time management, problem-solving, decision-making and friendships, and the mismatch with articulate speech and a good vocabulary causes a functional profile that is difficult for educationists or nonmedical readers to understand.
- By linking the medical condition to the learning disability, this paper aims to reduce misunderstanding and false accusations of laziness. Implications and the Way Forward provide early guidelines to families, educators and others.
- The 'final common pathway' that links shunted hydrocephalus to nonverbal learning disability is explained in comprehensible language.

Summary

A nonverbal learning disability is believed to be caused by damage, disorder or destruction of neuronal white matter in the brain's right hemisphere and may be seen in persons experiencing a wide range of neurological diseases such as hydrocephalus and other types of brain injury (Harnadek & Rourke 1994). This article probes the relationship between shunted hydrocephalus and nonverbal learning disability. Description of hydrocephalus and intelligence associated with hydrocephalus concludes with explication of the 'final common pathway' that links residual damage caused by the hydrocephalic condition to a nonverbal learning disability (Rourke & Del Dotto 1994, p. 37). The paper seeks to assist teachers, teacher aides, psychologists, guidance officers, support workers, parents and disability service providers whose role is to understand and advocate for individuals with shunted hydrocephalus and spina bifida.

Keywords Intelligence, hydrocephalus, neuron, shunt, white matter

Background

Children with shunted hydrocephalus and spina bifida usually present as highly communicative and in command of a good vocabulary, as having excellent rote memory skills and as learning best from repetition. Paediatrician and psychologist Dr James Loomis (2003) says these children normally do well during the early years of primary school but fall behind as task demands become more complex and abstract, and many struggle with a nonverbal learning disability (NLD). Right hemisphere dysfunction is believed to affect planning, organising and problem-solving abilities, the ability to process social cues, follow multistep directions and the ability to generalise. These interacting factors often cause frustration and misunderstanding for those working with young people when expectations cannot be achieved without extensions of time and one-on-one support. The difference between an illusion of competence and real functional ability is difficult to explain. This paper seeks to explain the link between the medical condition and the learning disability in an effort to reduce misunderstanding and false accusations of laziness. Implications and the Way Forward provide guidelines to help families and educational practitioners.

Causal background

It is recognised that both hemispheres are suited for different types of processing but typically complement each other in functioning. While neuroscientists are not in complete agreement about the cause of the disorder, Rourke's (1995) 'White Matter, Right Hemisphere Deficit' hypothesis is commonly accepted as a way to understand the syndrome's confusing development and presentation (Vacca 2001, p. 27). Rourke's explanation for NLD is based on the Goldberg & Costa (1981) model constructed from data and observations gained from investigations of human adults. Goldberg and Costa claim the right hemisphere is particularly equipped to handle tasks that involve intermodal integration, whereas the left hemisphere is predominantly suited to intra-modal processing (Goldberg & Costa 1981, p. 148).

This Goldberg and Costa's view involves the right hemisphere's ability to deal with unusual information demands for which no task-relevant or pre-existing behaviour exists 'in the subject's cognitive repertoire', while the left hemisphere is adept at handling the routinised, automated, stereotypic application of a particular task or plan once 'assembled' by the right hemisphere (p. 154). This notion suggests the right hemisphere can integrate information from several senses simultaneously such as interpreting gestures and facial expressions with spoken language to clarify full meaning, whereas the left hemisphere best handles well practised or rote learning pre-

sented in a step-by-step manner. These functional hemisphere differences were addressed in Gur *et al.* (1980) study. Findings demonstrated that:

- The ratio of grey-white matter is higher in the left hemisphere than in the right, meaning there is relatively more white matter than grey in the right hemisphere, 'particularly in the frontal and precentral regions' (p. 1226);
- **2.** The 'organization of the left hemisphere, relative to that of the right, emphasizes process or transfer within regions, or both, rather than transfer across regions' (p. 1226).

This indicates a relatively greater emphasis on interregional integration of the right hemisphere and on intraregional integration in the left. Tanguay (2002) suggests the dysfunction caused by a disproportionate amount of white matter in the right hemisphere vs. the left explains why NLD is often referred to as a right hemisphere syndrome. The intra-regional pattern of connectivity that characterises the left implies excellence in tasks that require focus on a single mode of performance. The right hemisphere's interregional connections lead to greater ability to process many modes of representation within a single task, in other words, complexity. Molenaar-Klumper (2002) explains these functional hemisphere differences by suggesting that information stored in the left side of the brain is more easily accessed because of a simpler structure, whereas information stored in the right hemisphere's branch-like structure appears more complex and difficult to access (p. 25).

Empirical studies of the Goldberg and Costa (1981) model were carried out on a group of children who exhibited extremely 'well-developed word-recognition and spelling skills but outstandingly poor performance in mechanical arithmetic' (Rourke 1989, p. 66). Resultant observations and generalisations illustrated that the group displayed deficiencies in inter-modal integration, problem-solving and concept formation especially in new situations. The group also had great difficulty benefiting from experiences that did not blend with known and practiced behaviours. They exhibited quite deficient right hemisphere capacities within a context of clear verbal strengths and single mode intramodal left hemisphere skills. This profile causes a dilemma for teachers and parents who do not consider that a student who is verbally fluent, with a large vocabulary and who achieves top spelling scores, could have a learning disability (Thompson 1997, p. 9). Conclusions and formulations drawn from research into right hemisphere developmental learning disabilities by other researchers such as Tranel et al. (1987), Voeller (1986), Weintraub and Mesulam (1983) are reported to bear a 'more than passing similarity' to those outlined in Rourke's 1982 model (Rourke 1989, p. 79).

Byron Rourke developed the 'White Matter' model in 1987–1988 to account for the neuropsychological development within the domains believed to characterise all children who display the NLD syndrome (Rourke 1989, p. 18).

Rourke expresses the White Matter NLD model in terms of three dimensions: (i) the more dysfunctional or damaged the white matter is, the bigger the chance an NLD will be present (ii) the developmental stage and type of white matter damage sustained has significant influence on manifestation of the NLD syndrome and (iii) the integrity of right hemisphere white matter is crucial for developing and preserving certain functions and damage will hinder learning that requires the integration of complex information (p. 113). These three principles indicate that a significant insult to the right hemisphere is 'sufficient' to cause the NLD syndrome, the 'necessary' condition being damage or destruction of the neuronal white matter which facilitates the transmission of information between hemispheres (Rourke 1989, p. 114). Although there is not complete agreement about the cause of the NLD syndrome, Rourke's White Matter model is a generally accepted way of recognising and understanding the syndrome. The more recent examination of neuropsychological, psychosocial and neuropathological characteristics of 66 children aged 5-14 years with shunted hydrocephalus by Fletcher et al. (1995) confirm that hydrocephalus clearly 'represents a prototypical NLD disorder' (p. 232).

What is white matter?

The brain has three main types of white matter fibres, commissural, association and projection. Commissural nerve fibres join right-left hemispheres. They cross the midline and interconnect similar regions in both cerebral hemispheres. There are three sets of commissural fibres - corpus collosum, anterior, posterior and habenular commissures, and hippocampal commissure fibres. The corpus collosum comprises the largest set of these white matter fibres (Rourke 1989). Association nerve fibres interconnect outer layers of tissue within the same hemisphere, back-front. They may be short when connecting neighbouring cells or long when connecting remote groups of cells (Rourke et al. 1983). Projection nerve fibres project down-up from the 'inbetween brain' to the cerebral hemispheres and from hemispheres to the 'in-between brain', brain stem and spinal cord (Rourke 1989, p. 115). The 'in-between-brain' is situated between the cerebral hemispheres and the brain stem (Nolte 1993, p. 3).

Link

Conditions such as hydrocephalus are expected to mainly affect the right-left commissural fibres and down-up projection fibres, leaving association fibres relatively intact (Rourke 1989). It is here that a link between hydrocephalus and NLD is made. Commissural fibres link the same areas

of opposite hemispheres, and projection fibres transmit information from the in-between brain to hemispheres and from hemispheres to the in-between brain, brain stem and spinal cord. Damage to right hemisphere white matter, which significantly interferes with these intercommunications between systems, would be expected to result in development of the NLD syndrome (p. 116).

Hydrocephalus

Hydrocephalus is a condition characterised by excessive cerebrospinal fluid (CSF) within the ventricles or 'caves of the brain'. It is caused by an obstruction that disrupts normal circulation pathways (Rowley-Kelly & Reigel 1993, p. 10). Cerebrospinal fluid is a clear fluid that bathes the brain and spinal cord tissues, and it is continuously reabsorbed (Llewellyn & Green 1987). About 600 ml of CSF is produced each day. Continuous secretion of CSF by three brain ventricles requires the body to absorb a specific amount of CSF to maintain a proper balance. Absorption occurs as CSF exits the 4th ventricle to the outer surface of the brain and spinal cord and finally enters the blood stream. This CSF production and absorption process 'ensures a stable fluid pressure' (Williamson 1987, p. 82).

Cerebrospinal fluid has three important life-sustaining functions. It keeps the brain tissue buoyant and acts as a cushion or 'shock absorber'. It acts as a vehicle for delivering nutrients to the brain, removes waste and flows between the head and spine to compensate for changes in the amount of blood within the brain (National Institute of Neurological Disorders and Stroke, 2001). Extra cell space, capillaries, lipids (organic compounds that are insoluble in water) and proteins found in white matter allow a normal brain to be bioelastic, with normal CSF pressure being lower than the brain's bioelastic limits 'so stress is distributed within the brain tissue' (Dennis 1996, p. 407). Hydrocephalus upsets this natural compensatory process, increases pressure within the ventricles and thus raises CSF pressure. The region around the ventricles receives the greatest stress and as it yields, the 'ventricles enlarge which increases the pressure' on brain tissue (p. 407). Enlargement of the ventricular system is expected to occur very close to the site of obstruction (Baron et al. 1995), and brain damage will occur within 12 h of CSF obstruction (Dennis 1996).

Hydrocephalus results from a number of congenital conditions including spina bifida. In the case of spina bifida, hydrocephalus is secondary to a structural malformation; therefore, it does not represent a definitive entity or clinical syndrome (Fletcher & Levin 1988). In young children, cerebral sutures are not fully fused and the skull expands to accommodate ventricular swelling which leads to an enlarged head, whereas in older children where sutures are fused, an enlarged head does not always accompany hydrocephalus (p. 264).

Hydrocephalus and shunting

Hydrocephalus is a major complication in 95% of spina bifida cases (Lutkenhoff & Oppenheimer 1997). Sometimes the raised pressure in and around the brain is temporary, and the hydrocephalus becomes naturally arrested, but usually the process is progressive. When fluid continues to collect, the pressure rises and must be relieved promptly to minimise brain damage (Dunning 1992, p. 6). To relieve the excessive pressure, a shunt system made of silastic tubing is inserted surgically into one of the ventricles of the brain through a burr-hole in the skull. With the shunt's tubing threaded beneath the skin, the spinal fluid drains continuously to a place where it can be disposed of, usually the abdomen or heart.

To ensure a one-way flow, a valve that includes a pumping chamber is incorporated into the system. Pressing the pumping chamber allows a medical practitioner to gauge shunt functionality. A valve that fails to fill after depressing the pumping chamber may indicate a malfunction between the catheter and valve. The shunt does not cure hydrocephalus but rather controls it. It prevents excessive head growth and allows the brain to grow normally. A well-placed shunt 'serves to increase the functional capabilities of the child's brain and generally eventuates in a better prognostic picture' (Rourke et al. 1983, p. 179). Blockage or obstruction of CSF through the shunt tubing is common and unavoidable because of normal growth and development. Ventricles may not return to normal size because of continuing force on ventricle walls, this force being 'directly proportional to the ventricular area' and pressure within the ventricle. Although shunting lowers CSF pressure, the surface area of the ventricles may remain enlarged and cause abnormal stress on the brain. Treatment in children therefore may only partially reverse changes within the nervous system and may not fully 'restore cognitive function' (Dennis 1996, p. 409).

Shunted hydrocephalus, shunt revisions and intelligence

For individuals with hydrocephalus and spina bifida, intelligence quotient (IQ) tends to correlate with the level of spinal cord lesion; the higher the lesion, the lower the IQ (Shaffer *et al.* 1985); Rourke 1989; Holler *et al.* 1995). Forty-two children with spina bifida in the 6–13 age range whose hydrocephalus was severe enough to require surgical intervention were found to have significantly lower Performance and Verbal scores than those of children with a history of unshunted hydrocephalus (Fletcher *et al.* 1996, pp. 192, 193). Most studies report lower IQ scores in children with spina bifida than in other aetiological groups which Anderson *et al.* (2001) contend would be expected 'given the major cerebral anomalies associated with the condition' (p. 194).

McLone et al. (1982) examined IQ results of 167 children with myelomeningocele. Results associated IQ scores with shunt complications and found those who were shunted but had no shunt complications had an average IQ of 95, but those who had shunt complications had an average IQ of only 73. Severity of hydrocephalus at birth was not found to be indicative of future intelligence, and the learning disability often associated with myelomeningocele was reported to be an 'acquired deficit primarily related to ventriculitis and/or meningitis' (McLone et al. 1982, p. 341). Fletcher and Levin (1988) report studies of children with myelomeningoceles, meningoceles and encephaloceles, which found 'the occurrence of hydrocephalus reduces intellectual skills' (p. 266). As a group, Fletcher and Levin (1988) say individuals with hydrocephalus associated with a neural tube defect have IQs that approximate one standard deviation below the mean, but in the absence of complications, individuals may function within the normal level of intelligence (Fletcher et al. 1995; Wills 1993).

Hunt and Holmes (1975) discuss the effects of a number of shunt revisions and subsequent intelligence in 66 children. Evidence indicated that the proportion of 'normal' to 'subnormal' children in their clinical population was not influenced by number of shunt revisions but rather age at which shunt revisions occurred was more important, generally the earlier the better. Although cognisant of studies unable to identify a relationship between numbers of shunt revisions and reduction in cognitive skills, Fletcher *et al.* (1995) suggest shunting and possibly shunt revisions have varying effects on cognitive abilities.

How shunted hydrocephalus damages white matter and causes NLD

The left hemisphere's pattern of connections is mainly intraregional, whereas the right hemisphere's is mainly interregional (Gur *et al.* 1980, p. 1226). The right hemisphere's importance for inter-modal integration of new and complex information, notably deficient in individuals with NLD, highlights the importance of white matter integrity for normal childhood development.

The brain and nervous system comprise many different types of cells, and the primary functional unit is a neuron. All sensations, movements, thoughts, memories and feelings result from signals that pass through neurons. Neurons consist of three parts: a cell body, dendrites and axon (Fig. 1). The cell body contains the nucleus. Dendrites resemble branches that extend out from the cell body to receive messages from other nerve cells. Signals that pass from dendrites and through the cell body may travel away from the cell body down the long slender axon cable. The terminal at the other end of the axon cable carries a message to another neuron (Eynon *et al.* 2002).

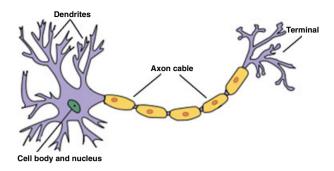


Figure 1 A Neuron. Adapted from Jarosz (2009).

A fatty molecule called myelin forms around the axon to provide insulation and help 'nerve signals travel faster and farther' (National Institute of Neurological Disorders and Stroke, 2003). This light-coloured fatty substance is also called 'white matter' which Tanguay (2002) defines as the brain's 'wiring system' (p. 24). Layered tissues of white matter called a myelin sheath surrounds nerve fibres and acts like an insulator in an electrical system. It ensures that messages sent by nerve fibres are not lost enroute. White matter covers axons that connect the layer of grey matter on the surface of a cerebral hemisphere with other centres of the brain and spinal cord. It therefore plays a critical role in the accurate and rapid transmission of messages within the brain, and damage to right hemisphere white matter will impair or 'short circuit' this process (Tanguay 2002, p. 25). This means that a signal may not be sent accurately or it may not reach its destination.

The myelination process begins prenatally and involves a gradual increase in the thickness of myelin sheaths that surround axons. This process continues through adolescence and is not complete until early adulthood during which time white matter is particularly vulnerable to disruption or damage (Anderson *et al.* 2001). Harnadek and Rourke (1994) found that a group afflicted from their earliest developmental stages with a hydrocephalic condition and who manifested the NLD syndrome did sustain significant damage or destruction of right hemisphere white matter from lesions caused by the hydrocephalic condition. Over time, Fletcher (1998) believes hydrocephalus may be associated with disruption of the myelination process and may result in overall reduction in brain size.

'The final common pathway' to NLD

Neurobehavioural characteristics that result from disturbance of the normal myelination process are reported to be impaired information processing capacity, slowed response speed and reduced attention (Anderson *et al.* 2001). For accurate and rapid transmission of messages, such capac-

ities require inter-modal integration of information from various sources and intact connections between hemispheres. This complex process relies heavily upon integrity of right hemisphere white matter. Damage or destruction of white matter is expected to short circuit the message transmission process which Rourke (1989) says is 'sufficient' to cause the NLD syndrome (p. 114). Given the significant damage to large portions of neuronal white matter principally in the right hemisphere expected from excessive accumulation of CSF, individuals with hydrocephalus are a Level 1 risk for manifestation of the NLD syndrome. Furthermore, hydrocephalus is one of the only disorders identified at Level 1 for which the neurobehavioural characteristics 'have been thoroughly investigated' (Fletcher et al. 1995; Tsatsanis & Rourke 1995).

This provides a biological link between hydrocephalus and a NLD. Damaged commissural fibres and projection fibres cause inter-communication problems which characterise a student with NLD. Such damage highlights the importance of white matter integrity for integration of new and complex information between hemispheres. Where deterioration of white matter interferes with right more than left hemisphere functioning because of grey-white ratios, the NLD syndrome would be expected to develop. Rourke and Del Dotto reaffirm this link when they hypothesise that 'disordered myelinisation and/or myelin functioning' is considered to be the 'final common pathway' that eventuates in the NLD syndrome (Rourke & Del Dotto 1994, p. 37).

Implications

This paper has implications for a range of stakeholders – teachers, teacher aides, psychologists, guidance officers, support workers, families and disability service providers who enact an advocacy role for individuals with shunted hydrocephalus and spina bifida. Academic literature reports that the clearly articulated speech of individuals with shunted hydrocephalus and spina bifida often causes misperception of real performance ability (Tew & Laurence 1979, p. 360; Culatta 1993, p. 171; Thompson 1997, pp. 8, 13). For teachers and aides, the difference between an illusion of competence and real functional ability is difficult to understand. Data collected during the author's doctoral study revealed much frustration on the part of teachers and aides working with such students:

A mother expressed strong "frustration dealing with teachers. Society hasn't changed ... the frustration with school is exclusion not inclusion". Despite her best efforts to advocate for the child, the mother believes teachers consider she is only the parent who wouldn't know anything yet the mother is the one confronted with the daughter's "sadness, unhappiness and the hard time she has accepting her disability (Rissman 2006, pp. 200–201).

Maybe as teachers we don't fully understand all the implications of her medical condition on issues like decision-making and problem solving. We think that "spina bifida has meant that she's ended up in a wheelchair but we know she's got some sort of intellectual ... but we would expect her to be able to make a decision 'do you want this green thing or do you want this red thing' and we think that's an easy decision to make. There's no right or wrong answer ... and maybe we don't understand ... it's not because she hasn't matured or grown up it's just that she can't like she's not skilled in that area because of her mental condition' (Rissman 2006, p. 225).

The Special Needs teacher has told us that Josie has not been diagnosed with an intellectual disability and yet there's so like ... we don't ... I don't think any of us understand. We've been told that she has no intellectual disability, there's nothing wrong with her, she hasn't been ascertained, there's nothing wrong with her mentally she only has a physical disability when it's quite plain to see that she doesn't just have a physical disability so we don't know. What is it and why won't anyone acknowledge there is something' (Rissman 2006, p. 224).

When colleagues showed incredible annoyance about the disorganisation and unpreparedness of a student with shunted hydrocephalus and spina bifida, the Special Education teacher stressed "they're not disorganised to annoy you and they cannot take responsibility for doing things ... it's not her fault and it's one of the things that if I'd had a dollar for every time I'd said to somebody 'it's actually a part of the condition, she's not doing it to upset you, please just build the extra prompt into your day" (Rissman 2006, p. 260).

When the link between the hydrocephalic condition and a nonverbal learning disability was explained, individual parents, teachers, aides and students expressed immense relief and understanding with comments such as 'that makes so much sense', 'now I get it' (Rissman 2006, p. 257). All teachers, teacher aides, parents and diagnosticians involved with students with shunted hydrocephalus and NLD will benefit from the contents of this paper.

The way forward

- 1. Shunted hydrocephalus occurs in 95% of spina bifida cases (Lutkenhoff & Oppenheimer 1997, p. 5). In view of the literature available, it is incomprehensible that the link between shunted hydrocephalus and NLD has not received wider recognition.
- 2. During undergraduate, postgraduate and in-service training, students and teachers should be encouraged to develop pathways for parents and teachers to share knowledge and problem solve together. Parents are in the best position to 'observe their child close at hand and to

- become staunch advocates for this child' (Thompson 1997, p. 21). Parents have 'child-specific expertise' which makes them a valuable resource for the teacher (Casile & Rowley-Kelly 1993, p. 293).
- 3. Parents want to be involved in the school's multidisciplinary team as 'advocates' and 'fully-enfranchised' members, say Casile and Rowley-Kelly (1993, p. 290). One parent believed they should advocate strongly for their child 'especially with the Education system, as it does not seem to fully understand the hidden problems associated with spina bifida' (Rissman 2006, p. 188). 'There's not a lot of schools who know a lot about spina bifida. It's not a known thing' said another parent (p. 240).
- 4. Teachers, aides and school psychologists need to gain more than a superficial understanding of the spectrum of developmental disorders of which an NLD is one. Teachers and aides need to listen to their own disquiet about any student who is struggling. They need to persistently question why a student cannot to do things one would expect they could do and demand answers that explicate the difficulties being experienced. Thompson (1997), Casile and Rowley-Kelly (1993) say medical and educational professionals should take time to listen to parental concerns which may indicate an NLD (p. 21). If treatment is not introduced fairly early 'on all appropriate academic and behavioural fronts', the prognosis tends to be 'quite bleak' (Rourke et al. 2002, p. 236).
- 5. Explanation that increases understanding will reduce teacher misunderstanding, unfair criticism and labels such as 'lazy', 'spoilt', 'molly-coddled' and 'uncooperative' (Rissman 2006, pp. 134, 260). A favourable prognosis for the student with NLD depends on the early identification and intervention if serious functional and long-term adjustment problems are to be minimised (Rourke et al. 1986). In addition to other biological, sociocultural and interpersonal factors, NLD 'appears to predispose those so afflicted to suicide risk', says Rourke (1989, p. 149), a situation that is intensified by teacher and peer misunderstanding over the prolonged school experience.

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