

# Mental health problems in children with neuromotor disabilities

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## Abstract

Mental health in children with neuromotor disorders is part of a dynamic system, including medical and developmental domains, family, school and community. Presentations are often complex and multifactorial, requiring a broad, individualized approach. A narrative overview of mental health symptoms in children with neuromotor disabilities is provided, along with recommendations for their assessment and management using the WHO's International Classification of Functioning framework.

**Key Words:** CP; Disability; HRQOL; ICF; Mental health; Spina bifida

Neuromotor disabilities are conditions of the nervous system, with motor deficits being their defining feature. Mental health problems in children with neuromotor disabilities are common, incompletely understood<sup>[1][5]</sup> and “likely determined by the interacting influences of multiple biological, neuropsychological, and social factors”.<sup>[5]</sup> Their clinical presentations often reflect a dynamic<sup>[6]</sup> or transactional relationship between the child living with a disability and the environment (eg, the effect of caregiving needs on caregiver fatigue).<sup>[7]</sup> The purely medical model must give way to “diagnosing the child-world interaction”.<sup>[8]</sup>

The present statement offers a narrative overview of mental health symptoms in children with various neuromotor disabilities, followed by recommendations for their assessment and management that utilize the WHO's International Classification of Functioning (ICF) framework. The ICF system has provided a new context for thought and practice in the field of childhood disability by encouraging an approach to care that puts more emphasis on a child's function (“activity”) and social engagement (“participation”) than on their impairment.

## Health Conditions

### Neuromotor disorders

Common disorders that affect movement, posture and manual abilities include cerebral palsy (CP), muscular dystrophy and spina bifida. Neurological impairment is attributed to lesions that are static (as in CP)<sup>[9]</sup> or progressive (as in muscular dystrophy). Children may present with combinations of weakness, hypotonia, spasticity, dystonia, contractures, sensory disorders, cognitive deficits and other medical comorbidities. There is great variability of function within the many diagnostic categories and among different classification approaches.<sup>[10]</sup>

### Mental health problems associated with neuromotor disorders

Children and adolescents with neuromotor disorders have more mental health symptoms than the general population,<sup>[11]</sup> including difficulties with social skills, self-esteem, behaviour, anxiety, mood and attention.<sup>[5][12]</sup> Assessment may be complicated by communication problems (eg, difficulty speaking), atypical presentations of motor disability and neurodevelopmental disorders (eg, attention-deficit hyperactivity disorder or its symptoms), and challenges to obtaining clinical history.<sup>[13][14]</sup> Physicians often resort to describing ‘features’ without diagnosing specific categorical disorders.

## Body Structures and Functions

### Musculoskeletal pain

Pain is associated with reduced participation in social or other activities, a lower quality of life and mental health problems.<sup>[15][16]</sup> Children with CP experience physical pain in direct relation to the severity of their functional disability.<sup>[16][17]</sup> Possible sources of chronic pain include medical procedures, neuromuscular disturbances, such as dystonia, and musculoskeletal causes such as a hip dislocation.<sup>[9]</sup> Pain in children with neuromotor disabilities has been found to be associated with feelings of isolation, frustration and sadness, as well as with caregiver observations of anxiety,<sup>[18]</sup> increased crying (with or without movement),<sup>[16]</sup> difficulty concentrating, irri-

tability and lower activity levels.<sup>[19][20]</sup> Cognitive behavioural therapy may help to mitigate the effects of pain on mental health.<sup>[18][21][22]</sup>

### Medical comorbidities

Children with neuromotor disorders often have medical comorbidities. Seizures and the medications used to control them may affect cognition, motor and emotional-behavioural functioning. Dysphagia includes feeding difficulties caused by abnormal oral, pharyngeal and esophageal phases of deglutition, which also increase the risk for aspiration and recurrent pneumonia. Gastroesophageal reflux and frequent or chronic constipation can lead to pain and nutritional problems. Sleep disorders are often multifactorial and may relate to pain caused by skin ulcers, neuromuscular and musculoskeletal problems, gastroesophageal reflux disease or constipation, or to obstructive sleep apnea, the inability to change sleep position, as well as to difficulties with parent-child interaction (eg, with limit-setting).<sup>[9]</sup>

## Activity

### Motor

Levels of motor impairment that are not severe have been associated with both worse<sup>[3][23]</sup> and better<sup>[24]</sup> health-related quality of life (HRQOL). As these findings imply, HRQOL, mental health and motor disability have a complex interrelationship.<sup>[23][24]</sup> Many children with CP have more positive perceptions about their situation than what may be expected by others, including their parents. While internalizing problems may lead to less engaged or irregular physical and social activity, which in turn is associated with lower child-reported HRQOL, externalizing behaviours (ie, being disruptive or aggressive) correlate negatively with lower parent-reported HRQOL but positively with child-reported HRQOL. These findings highlight that behaviour problems, being subjective and perspective-dependent, are difficult to define in this population.

### Communication, cognition and learning

Cognitive disability is strongly associated with mental health disorders.<sup>[25]</sup> Neuromotor disorders often involve social-emotional, executive and cognition dysfunction,<sup>[26]</sup> mild to profound intellectual disability and learning disabilities. For example, spina bifida is associated with nonverbal learning disorder, attention-deficit hyperactivity disorder, executive dysfunction and hydrocephalus (with possible complications from ventriculoperitoneal shunting such as increased intracranial pressure from shunt failure and central nervous system infections).<sup>[27]</sup>

Motor impairments can impede cognitive tests that are based on verbal or pencil-and-paper responses and appropriate assessment of level of function. Individuals with a severe motor impairment (eg, dyskinetic CP) can also have trouble understanding spoken language, expressing themselves or achieving

typical cognitive milestones.<sup>[28]</sup> The importance of accurately determining a child's levels of function and ability cannot be overstated in regard to shaping expectations for emotional-behavioural maturity, academic demands and peer interactions. When abilities and expectations are mismatched in the child-environment interaction, symptoms of emotional stress can result, such as internalizing or externalizing symptoms of stress.

## Environment

### Family

The biopsychosocial relationship of children living with neuromotor disability and their environment is especially complex because it includes family, school and community.<sup>[5]</sup> The parents of children with a physical disability can bear a tremendous long-term burden of providing care. Unsurprisingly, such parents are statistically less healthy, both physically and psychologically, compared with parents of children without disabilities.<sup>[29]</sup> A child's behavioural difficulties can undermine a parent's sense of competence,<sup>[6][30]</sup> reinforce problems with attachment, and compound parental stress, spousal relationship difficulties and caregiver depression. Such stressors are associated, in turn, with difficult child behaviours.<sup>[31]</sup> Parental mental health problems increase the risk for mental health problems for any child, particularly in the developmentally critical early years.<sup>[32]</sup> However, the strategic use of respite care may help to decrease caregiver stress and enhance family environments.<sup>[33]</sup>

### School

Positive academic and social involvement at school is a protective factor for health in the longer term. However, many children with neuromotor disabilities form fewer friendships, have fewer social skills and experience social isolation and victimization more often than their typical peers.<sup>[34]</sup> Motor disorders can increase risk for neglect in the classroom, such as when insufficient time is allotted to children to use their speaking devices. On the other hand, higher cognitive functioning is predictive of fewer social difficulties,<sup>[4]</sup> and personalized classroom supports have been strongly associated with increased participation.<sup>[35]</sup>

### Community

Research is ongoing into the social effects of environment, specifically of better access to recreational activities and opportunities for interaction, on the lives of individuals with neuromotor disabilities. It is already well known that participation in physical activities is negatively impacted by limited financial resources, by environmental factors such as a lack of open space, rough terrain or inadequate transport, and by lack of inclusiveness.<sup>[36]</sup> One study found that exposure to other individuals with disabilities supported more favourable attitudes in children concerning their own disabilities.<sup>[37]</sup>

**TABLE 1****Review of systems using the WHO's International Classification of Functioning framework****Body structures**

- Specialized clinicians (eg, an orthopedic surgeon) should monitor for secondary musculoskeletal disorders
- Assess and treat constipation and gastroesophageal reflux disease (especially with unexplained sleep or feeding difficulties), voiding difficulties, sleep disturbances and seizures
- Review feeding, including method, timing and environment, and manage symptoms of coughing, gagging and choking; consider referral to a feeding and swallowing team at a local children's treatment centre or paediatric hospital
- Inspect the skin, back and joints, particularly under supportive devices. Consider reassessment by an orthotist, occupational therapist or orthopedic surgeon
- Ensure regular follow-up with the child's dentist, optometrist and/or ophthalmologist and audiologist

**Functions**

- Determine developmental levels across functions (ie, "developmental age")
- Note mismatches between "developmental age" and expectations across environments
- Therapists should attend medical appointments or provide a report summarizing findings
- Consider augmentative communication methods (visuals, technology) through speech and language therapy or a technology access referral
- Supplement monitoring with a mental health screening checklist to help track symptom severity over time (eg, [http://www.brightfutures.org/mentalhealth/pdf/professional/ped\\_symptom\\_chklst.pdf](http://www.brightfutures.org/mentalhealth/pdf/professional/ped_symptom_chklst.pdf))

**Home environment**

- Review family structure, physical environment and parent-child interactions
- Identify the family's psychosocial supports and stressors (eg, bereavement, moves, illness, financial difficulties, conflict and separations) and overall well-being
- Consider referrals for social work, case coordination (eg, at a children's treatment centre) or adult mental health care
- Consider discussing referral to an early interventionist (early developmental therapist) or a behaviour or mental health therapist if you have concerns regarding parent-child interactions
- Consider discussing potential benefits and options for referral for parental respite care

**School environment**

- A collateral history should be obtained directly from the child's teacher (verbal or written)
- A review of the child's functioning and participation in school should include:
  - classroom placement (integrated, specialized and/or supported) and level of work
  - school's understanding of the child's function and mental health symptoms
  - school interventions to address mental health symptoms (eg, difficult behaviours)
  - psychoeducational or other assessments
  - assistive devices or supports (seating, communication tools)
  - the child's level of participation across school activities
  - the parent-teacher relationship

- Encourage parents to meet regularly with school personnel
- Provide an advocacy letter outlining the child's diagnosis, function levels and specific needs

#### Participation and individual factors

- Review and emphasize the benefits of recreation
- Ask the child about favourite activities ("What do you find the most fun?")
- Encourage parents to communicate with community agencies about recreational programs
- Discuss the potential benefits of being active with and exposed to other individuals with disabilities
- Consider involving a physiotherapist or other therapist to help access recreational opportunities
- Consider re-referral to a physiotherapist or occupational therapist to assess whether a child's mobility is optimal (eg, is a motorized chair needed?)

## Participation

Participation has been defined by the WHO's ICF framework as "involvement in life situations" and is a key determinant of mental health.<sup>[38]</sup> In children with a neuromotor disability, participation is a "multi-determined phenomenon"<sup>[38]</sup> associated with motor and cognitive function,<sup>[39]</sup> family factors,<sup>[40]</sup> accessibility within the home and community, favourable attitudes of people sharing the child's household and neighbourhood,<sup>[41]</sup> the child's own ability to access and develop specific personal interests, and a more positive perception by parents concerning the extent of their child's constraints.<sup>[6]</sup>

## Personal Factors

Every child has a unique temperament that affects their interaction with the world, including traits of adaptability, intensity, persistence, activity level, attention, predominant mood and sensory sensitivity. As with any child, the ability to express and act on preferences, feeling capable and experiencing companionship will affect levels of participation.

## Conclusion

Children with neuromotor disabilities often experience mental health symptoms, which can involve multiple body systems and environmental factors which, in turn, can directly impact personal functioning and social participation. For the health care provider, family factors and quality of life are integral components of assessment and intervention. A careful systemic review examining body structures, functional abilities, home and school environments, participation levels and personal factors should be conducted (Table 1).<sup>[9]</sup> Appropriate physical and psychosocial examinations usually require multiple visits, at least initially.

The following recommendations may help health care providers to assess and promote mental health in the child or adolescent living with a neuromotor disability:

- Mental health should be considered contextually, in the child-environment system, necessitating a broad assessment of ICF domains.
- Addressing mismatches in a child's multiple environments (home, school, recreation) compared with functional abilities (motor, communication, social-emotional skills) can improve participation levels. Physicians should consider providing a medical letter to caregivers with specific information about a child's functional abilities, medical diagnoses and recommended supports, such as assistive technologies and strategies.
- A consistent coordinating physician is best able to identify and manage the many possible sources of physical discomfort that may be affecting a child's mental health symptoms.
- A coordinating physician can also be a source of information, compassionate care and referrals for parents who have difficulty meeting their child's complex needs.
- The child's history should be compiled directly from multiple sources, including from the child and his/her family members, educators and therapists, through face-to-face meetings, written reports and telephone conversations.

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