

Children with Profound Intellectual Disabilities: Understanding Their Unique Needs and Ensuring Quality Care

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Description

Children with profound intellectual disabilities require specialized care and support due to the significant impact of their cognitive impairments on their overall development and functioning. Profound intellectual disabilities are characterized by severe limitations in intellectual functioning and adaptive skills. In this article, we will explore the challenges faced by children with profound intellectual disabilities and discuss strategies for providing them with appropriate care and enhancing their quality of life.

The nutritional assessment of children with neurological impairment using European Society for Paediatric Gastroenterology, Hepatology and Nutrition guidelines is time-consuming and requires trained staff. CP is the major subgroup in the guidelines, which recommend looking for warning signs of undernutrition based on low weight, low triceps skinfold thickness (TSFT), and low mid-upper arm fat or muscle area. In addition to these red flags, physical signs of undernutrition and faltering weight and/or failure to thrive should be observed. This type of assessment is not performed routinely in Denmark, and because other more applicable screening procedures are not available, individuals with nutritional problems may not be identified and given relevant nutritional support. For the general paediatric population at least five malnutrition screening tools are available that address malnutrition in hospitalized patients. Three of these have been evaluated, but the inconsistent results prevent recommending any of them for clinical practice, underlining the general challenges of nutritional screening which are heightened further in children with CP.

Understanding Profound Intellectual Disabilities

Profound intellectual disabilities are a form of intellectual disability characterized by severe cognitive impairments. Here are some key aspects of profound intellectual disabilities:

Intellectual Functioning: Children with profound intellectual disabilities typically have significantly below-average intellectual functioning. They may have limited or absent verbal communication skills and may struggle to understand and

process information. These limitations can affect their ability to learn, problem-solve, and interact with their environment.

Adaptive Skills: In addition to intellectual functioning, profound intellectual disabilities also impact adaptive skills. Adaptive skills include daily living activities, communication, socialization, and motor skills. Children with profound intellectual disabilities often require assistance and support in all areas of adaptive functioning.

Physical and Health Challenges: Children with profound intellectual disabilities may have associated physical and health challenges. These can include mobility limitations, sensory impairments, seizures, feeding difficulties, and increased susceptibility to infections. These physical challenges further complicate their care and require specialized attention.

Challenges and Strategies for Care

Children with profound intellectual disabilities require comprehensive care that addresses their unique needs. Here are some common challenges they face and strategies to support their well-being:

Communication and Interaction Challenges: Children with profound intellectual disabilities often face significant challenges in communication and social interaction. Here are some strategies to AAC methods, such as picture communication boards, sign language, or assistive communication devices, can support expressive and receptive communication. AAC enables children to express their needs, preferences, and emotions, enhancing their interaction with others.

Sensory-based strategies, such as using visual cues, simplified language, and structured routines, can help children with profound intellectual disabilities better understand and engage with their environment. Creating a sensory-friendly environment can reduce sensory overload and promote comfort. Children with profound intellectual disabilities often require assistance with ADLs, such as dressing, bathing, feeding, and toileting. Here are strategies to support their daily care needs:

Developing individualized care plans, in collaboration with healthcare professionals and caregivers, ensures that the specific needs of each child are met. These plans should include

strategies for personal care, feeding, medication management, and therapeutic interventions. Providing adaptive equipment, such as specialized feeding utensils, modified seating, or assistive devices, can enhance children's independence and participation in daily activities. Occupational therapy can assess and recommend appropriate adaptations and assistive devices.

Children with profound intellectual disabilities benefit from a multidisciplinary approach to care. Here are key professionals who can contribute to their well-being:

Developmental pediatricians specialize in diagnosing and managing developmental disabilities. They can provide guidance on medical interventions, monitor growth and development, and coordinate care with other specialists. Occupational and physical therapists play crucial roles in supporting children's motor skills, sensory integration, and functional abilities. They can provide therapeutic interventions, recommend adaptive equipment, and work on enhancing children's physical capabilities. Special education professionals, such as special educators or behavior therapists, can create individualized education plans (IEPs) and implement strategies to support learning, behavior management, and social-emotional development. They collaborate with families and schools to ensure appropriate educational support.

Interpreting growth parameters of children and adolescents with CP is also a challenge. There are no accepted standards for evaluation of anthropometry since existing CP growth charts are not recommended in clinical practice. As a result, a standard

method on how to perform nutritional screening and interpret anthropometry in children and adolescents with CP is lacking. Growth in children and adolescents with CP is not comparable to growth in typically developing children interpreted by World Health Organization growth charts. Children with CP are at risk of being incorrectly characterized as underweight or malnourished when evaluated using regular standards, which is also an issue when possible overweight is assessed in this population. From 1994 to 2004, the prevalence of obesity among children with CP increased from 7.7% to 16.5%, defined using Centers for Disease Control and Prevention criteria. Assessment using the same standards that are applied to typically developing children could potentially lead to underreporting of overweight among children and adolescents with CP. This aspect is also important to address because obesity, similar to underweight, is correlated to various negative health consequences.

Children with profound intellectual disabilities require specialized care and support to maximize their quality of life. By understanding their unique needs, implementing strategies for communication, daily care, and involving a multidisciplinary team, we can enhance their development and well-being. Emphasizing inclusive environments, fostering supportive relationships, and promoting individualized interventions are key in ensuring that children with profound intellectual disabilities receive the care and support they need to thrive and lead fulfilling lives.