Arch Psychiatry. 2025;3(1):61–71.

The Archives of Psychiatry | Commentary

Pain in People with Profound Intellectual and Multiple Disabilities

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Received date: June 24, 2025, **Accepted date:** October 13, 2025

Citation: Bourin M, Absil P. Pain in People with Profound Intellectual and Multiple Disabilities. Arch Psychiatry. 2025;3(1):64–71.

Abstract

The inability to communicate verbally does not in any way negate the possibility that an individual may be experiencing pain and may need appropriate treatment to relieve their pain. Pain can be expressed differently from one person to another. It can be difficult to decode and interpret and, as a result, can be underestimated by caregivers, particularly in people with multiple disabilities, due to their sensory specificities and unique communication modalities. Pain can thus result in an exacerbation of other somatic disorders (e.g., epilepsy) and behavioral disorders. People with multiple disabilities may also express pain differently depending on their environment and the type of pain (discomfort related to physical placement, temporary pain related to manipulation, chronic pain related to a health problem, etc.). Spasticity, dystonia, the oral and dental system, the digestive system (gastroesophageal reflux, constipation) and osteoarticular characteristics are often the cause of pain in people with multiple disabilities. The psychological challenges faced by people with multiple disabilities, such as separation and dependency-related living conditions, should also be considered. They experience each painful event individually, as their abilities to reason, gain perspective, and self-regulate are unique.

In this population, pain perception is influenced by the interplay of neurodevelopmental variations and complex medical conditions. Conventional methods of pain evaluation, which rely heavily on verbal self-report or observable reactions, often fall short in accurately representing the lived experiences of individuals with pain in people with profound intellectual and multiple disabilities. As a result, discomfort may manifest through subtle shifts in behavior, posture, or physiological parameters signs that require keen observation and a deep understanding of each person's baseline functioning.

Family members and clinicians alike must cultivate a nuanced awareness of the myriad ways pain can present itself. This may include increased agitation, withdrawal, moaning, changes in facial expression, or altered sleep and appetite patterns. External stressors ranging from environmental stimuli to procedural interventions can further complicate the clinical picture. Consequently, multidisciplinary collaboration and ongoing education are integral to improving recognition, assessment, and relief of pain for people with profound intellectual and multiple disabilities.

Pain in people with profound intellectual and multiple disabilities remains a complex clinical challenge, due to difficulties in recognizing, assessing, and managing their unique pain experiences. Sensory, motor, and cognitive impairments can lead to atypical signs of discomfort that are frequently missed or misinterpreted by healthcare professionals and caregivers. Recent research emphasizes the importance of a multidisciplinary approach to pain identification, considering behavioral cues, physiological changes, and contextual factors. It is crucial to adapt assessment tools and pain management strategies to the specific needs and capacities of this population, thus ensuring compassionate and individualized care.

Keywords: Autism, People with profound intellectual and Multiple disabilities, PMID, Pain

Introduction

The inability to communicate verbally does not in any way negate the possibility that an individual is experiencing pain and may need appropriate treatment to relieve their pain. The expression of pain can be different from one person to another. Due to their sensory differences and unique communication methods, people with profound intellectual and multiple disabilities are often misunderstood and underestimated by caregivers. Pain can thus result in an accentuation of other

somatic disorders (for example, epilepsy) and behavioral disorders [1]. People with multiple disabilities (PIMD) can also express differently depending on their environment and the type of pain (discomfort related to the physical installation, temporary pain related to manipulation, chronic pain related to health problems, etc.) [2]. Spasticity, dystonia, the oral and dental sphere, the digestive system (gastroesophageal reflux, constipation) and osteoarticular characteristics are often the cause of pain in people with multiple disabilities. It is also important to consider the psychological suffering of people with multiple disabilities (for example, in connection with separation, living conditions inherent to their dependency, etc.). Indeed, they may experience every painful event to the extent that their possibilities for self-reasoning, relativization and reasoned regulation are unique. Challenges and expected outcomes are recognition of the existence of different forms of pain expression in PMID, identification and assessment of pain, prevention, and treatment of pain.

Pain Due to Excess Nociception

Daily life activities and mobilizations

Daily activities such as bathing, mobilization, and meals can cause pain of varying severity in PIMD [3]. This pain can be well-received depending on the environmental and emotional context. This pain is common among patients with daily activities such as bathing, mobilization, and meals can cause pain of varying severity in PIMD [2]. It also includes care procedures provided by nurses, such as dressings, burn and pressure ulcer care, and gastrostomy placement. It also occurs during mobilization in physiotherapy, rehabilitation, and during transfers to the examination table or changing room. Pain from care and movement is often overlooked or seen as unavoidable. Preventive treatment plays a significant role, and individuals responsible for caring for people with multiple disabilities should be trained in mobilization techniques to minimize the likelihood of pain [4]. It is also necessary to consider supporting care and mobilizations such as verbalizing the actions that will be provided and accepting the patient's pace.

During sessions in the psychomotor room, participants are assisted out of their chairs and guided to the mats. During these mobilizations, particularly with the help of the patient's lift, pain may occur. It is then important to verbalize this, to support the mobilization and to reassure the young person. Leaving the supportive and comfortable chair, which serves as a kind of protective shell or exoskeleton, may be challenging. This process can cause elevated muscle tone and could subsequently result in further contractures and discomfort [5].

The multidimensional nature of pain in this population calls for vigilance not just in direct clinical encounters, but within the broader scope of daily living. It is important to acknowledge that pain can originate from commonly neglected factors, such as extended periods of immobility during routine tasks or the cumulative impact of minor injuries that may remain unreported due to communication challenges. Caregivers play a vital role in both prevention and intervention, relying on an intimate knowledge of the individual's usual demeanor and physical state to notice even the faintest signals of distress.

Moreover, anticipatory strategies such as proactively addressing known triggers and employing comfort measures before, during, and after essential daily events can mitigate suffering before it escalates.

Furthermore, the anticipation and management of pain must be integrated into every aspect of daily care. Regular monitoring for subtle behavioral or physiological changes can alert caregivers to the presence of pain before it becomes acute or overwhelming. Interventions should be proactive, including the use of comfort measures, adaptive equipment, and environmental modifications tailored to each individual's needs. Clear, empathetic communication—through gestures, visual cues, or assistive technology—facilitates trust and allows individuals to participate in their own care as much as possible. Ultimately, fostering an environment of patience, vigilance, and respect for the person's autonomy is essential in both preventing unnecessary suffering and ensuring that pain, when present, is swiftly recognized and addressed.

The anticipation and management of pain should be woven into every aspect of daily care for people with profound intellectual and multiple disabilities. Caregivers need to remain attentive to subtle behavioral or physical changes that might signal pain, allowing them to detect discomfort early, before it becomes severe. Interventions should be proactive utilizing comfort strategies, adaptive devices, and environmental adjustments that are specifically tailored to each individual's requirements. Maintaining open, empathetic communication through gestures, visual support, or assistive tools helps build trust and enables individuals to be as involved as possible in their own care. Fostering patience, vigilance, and respect for autonomy is essential to prevent unnecessary suffering and ensure pain is quickly addressed.

Environmental adaptations, careful handling, and supportive devices help maintain dignity and comfort. Ongoing collaboration between professionals and families ensures responsive, compassionate pain management.

Digestive pain

Swallowing disorders are a real source of suffering. The primary intervention consists of preventive treatment alongside specialized training in feeding techniques and the management of swallowing disorders. Mealtimes should remain a time for sharing and enjoyment [6]. To this

end, professionals have established a spatial, temporal, and psychological framework to build trust in the child and support them as best as possible without infantilizing them. This means that we act according to their abilities, desires, and condition. It is important to respect their rhythm during meals to avoid any risk of choking.

It is not uncommon to encounter patients who are underhydrated because they cannot express thirst or serve themselves. They need to stay hydrated all day. Underhydration is painful, causing significant muscle pain, dry mouth, and decreased sweating. This can lead to confusion syndrome or even coma [7].

Esophagitis and gastroesophageal reflux are widely present in PIMD. This is the passage of gastric contents into the esophagus, which may result from malfunctioning cardia; the muscle located at the junction of the esophagus and stomach. It leads to heartburn, regurgitation, vomiting, and sweating [8].

Constipation is almost constant in PIMD. It can be due to immobility, dehydration, diet, certain medications, etc. If left untreated, it can cause intense abdominal pain, severe obstruction, and confusion [9].

Dental pain

Individuals with multiple disabilities are particularly susceptible to advanced oral diseases, which can result in significant pain. As detailed in the appendices, certain systemic disorders commonly associated with disabilities can have direct consequences on oral health [10].

Maintaining effective oral care is often challenging and, in some cases, neglected entirely. The act of providing oral hygiene itself may cause considerable stress for people with multiple disabilities, sometimes making it necessary for medical professionals to perform dental treatments under general anesthesia. Oral diseases are often identified late, indicating that dental pain in this population is underreported [11].

Otorhinolaryngology pain

Ear, nose, and throat (ENT) pain is typically brief, intense, and usually treatable. Otalgia specifically refers to ear pain, which can be severe due to the rich nerve supply in the outer and middle ear (including the trigeminal, facial, spinal, vagus nerves, and C2/C3 cervical roots). Ear pain often results from infections and may also stem from nasal, sinus, or pharyngeal issues.

Orthopedic pain

Pain often arises from multiple disabilities, such as spinal conditions like idiopathic scoliosis, which affects vertebrae in all planes. Rapid progression during puberty may require bracing or spinal surgery, both of which can cause persistent pain if not addressed.

Tendon retractions can result in hip subluxation or dislocation, while bone demineralization increases the risk of pathological fractures. Hand and foot deformities due to hypertonia (spasticity or dystonia) are also common and may cause pain and discomfort.

Intra- and post-operative pain

Pain is an integral part of surgical procedure. A distinction must be made between two types of pain.

Intra-operative pain: that is, pain during the surgical procedure itself, which requires general or local anesthesia, depending on the extent of the procedure.

Post-operative pain: pain following surgery. This pain is important to manage during the recovery and rehabilitation phase. It requires drug-based analgesia [15].

Another crucial consideration is the management of pain related to invasive procedures and rehabilitation interventions, which often accompany the complex care trajectories of individuals with profound and multiple disabilities. While anesthesia and analgesia are critical during intra- and postoperative periods, the anticipation and mitigation of pain must extend beyond surgical events, encompassing routine medical care such as injections, catheterizations, or physiotherapy sessions. Even minor interventions can provoke considerable distress due to heightened sensory sensitivity or difficulties in communication. Therefore, initiative-taking strategies including careful preparation, clear explanation suited to cognitive abilities, and the implementation of individualized comfort measures are indispensable. These approaches, coupled with multidisciplinary collaboration, not only minimize suffering but also foster trust and resilience, paving the way for improved participation in ongoing therapeutic regimens and enhancing overall well-being.

Epilepsy

Epilepsy frequently occurs in individuals with multiple disabilities and is often secondary to brain injury associated with these disabilities. Seizures are characterized by abnormal electrical discharges of neurons, referred to as hypersynchronous neuronal activity. These discharges may affect all neurons, resulting in "generalized" seizures, or may be limited to specific groups, producing "partial" seizures. Clinical presentations can include absences, motor symptoms, or autonomic symptoms [16].

There is consideration regarding whether epileptic seizures are associated with pain manifestations and headaches [17]. In addition to neurological and orthopedic issues, it is important

to monitor pain related to gastrointestinal disturbances, urinary tract conditions, and respiratory complications. Such pain can be diffuse or localized and may present atypically, making diagnosis more complex, particularly for individuals who have difficulty communicating discomfort. Acute or chronic pain may also follow surgical procedures, trauma, or routine medical interventions, highlighting the importance of thorough pain assessment and personalized management approaches.

For those with communication difficulties, behavioral and physiological cues like muscle tension, facial expressions, withdrawal, or heart rate changes can signal pain or distress.

Given these complexities, the accurate detection and assessment of pain become paramount especially in individuals who may have limited verbal communication. Multimodal pain assessment tools, observation of nonverbal cues such as changes in posture, facial expressions, or behavioral disturbances, and input from caregivers are crucial. Even subtle deviations from an individual's baseline demeanor should prompt consideration of underlying pain.

The intersection of chronic medical conditions, frequent medical interventions, and neurological comorbidities underscores the necessity for vigilance and adaptability in pain management strategies. Personalized care plans must be dynamic, evolving in response to growth, developmental changes, and shifting clinical presentations. By prioritizing the continuous evaluation of pain and its sources, clinicians and caregivers can intervene more promptly and appropriately, preventing unnecessary suffering and promoting optimal functioning to the fullest extent possible.

Detecting these signs early enables timely intervention to prevent chronic pain and reduced mobility.

Effective pain management requires a comprehensive approach, incorporating medication, physical therapy, psychological support, and daily care adjustments. Interdisciplinary teamwork and attentive care are essential to reduce suffering and improve comfort in complex cases.

Furthermore, it is important to note that the onset of adolescence sometimes leads to an increase in the number of seizures. It is common to have to change treatment when entering puberty.

The case of non-mobilization

Patients in seat corsets who cannot move are at risk for pressure sores from prolonged tissue hypoxia [18].

Non-mobilization, meaning the inability or profound limitation in movement, presents distinct challenges and is a common scenario among individuals with significant multiple disabilities. Prolonged immobility not only contributes to deconditioning of muscles and joints but also increases vulnerability to a range of secondary complications, including pressure ulcers, contractures, circulatory difficulties, respiratory infections, and deep vein thrombosis. The resulting discomfort or pain often emerges insidiously, sometimes without overt physical signs, especially in those incapables of expressing their distress.

Assessment of pain in the context of non-mobilization requires an initiative-taking and systematic approach. Clinicians and caregivers must be vigilant for subtle changes in physical presentation: unusual posture, reduced participation in activities, changes in skin coloration, or unexplained agitation. Furthermore, attention to the environment such as prolonged positioning in bed or wheelchair, inadequate support surfaces, or missed opportunities for assisted movement can provide important clues about potential sources of discomfort.

Intervention strategies should emphasize both prevention and prompt response. Regular repositioning, supportive devices to maintain alignment, and therapies to promote even limited mobility are foundational. In addition, incorporating sensory stimulation and gentle range-of-motion exercises may alleviate some of the musculoskeletal pain associated with inactivity. Equally critical is the involvement of a multidisciplinary team physiotherapists, occupational therapists, nurses, and family members—to tailor interventions to each individual's unique needs and capacities.

Effective pain management for non-mobilized individuals demands ongoing communication and coordination among all members of the care team. By fostering an environment of attentive observation and early intervention, clinicians can minimize suffering, enhance comfort, and support the best possible quality of life for those who face the compounded challenges of non-mobilization and complex disability.

Lack of movement also leads to muscle stiffness and poor circulation. Preventative measures include regular repositioning, special cushions, and attentive nursing care. Caregivers should closely monitor for signs of discomfort or pain, using behavioral cues and physical indicators in patients unable to communicate verbally.

other causes of pain due to excess nociception

Consider abdominal, urinary (infections, stones) [19], and pulmonary pain, as well as trauma from falls or self-harm. Watch for seasonal infections that may cause pharyngeal or abdominal pain. Menstrual pain is a factor relevant to women's health.

Neuropathic Pain

Neuropathic pain, caused by nerve damage or dysfunction from conditions like diabetes, shingles, or central nervous system disorders, can be mild or severe and may persist or fluctuate. It can originate from the peripheral nerves, spinal cord, or brain, and often requires a combination of treatments such as medication, physical therapy, counseling, or surgery [20].

Neuropathic pain differs from nociceptive pain originating within the nervous system rather than from direct tissue injury. This condition commonly presents as persistent discomfort interspersed with intermittent sharp sensations, and may be challenging to diagnose, especially in patients with multiple disabilities. "Mixed pain," which involves both neuropathic and nociceptive elements, requires careful assessment and multidisciplinary, personalized management.

The central nervous system is made up of the brain and spinal cord, while peripheral nerves connect to organs and limbs. Damaged nerves can send faulty pain signals, causing neuropathic pain that is common but often underestimated, especially in those with multiple disabilities or progressive encephalopathies [21]. This pain typically presents as a persistent background sensation with sudden sharp episodes (flashes) and may trigger acute dystonia. Even light touch can cause abnormal pain responses. Pain types can also be mixed, combining neuropathic and excessive nociceptive pain [22].

Difficulties Identifying Pain

PIMD patients frequently experience pain from birth due to multiple health issues, repeated surgeries, medical care, and hospitalizations [23]. Pain in individuals with multiple disabilities can be especially prevalent during puberty and adolescence [24]. Puberty involves physical and psychological changes leading to adulthood, including the development of secondary sexual characteristics, rapid growth, behavioral shifts, and increased bone mass and BMI. The timing of puberty varies due to neuroendocrine and environmental factors [25].

Puberty brings physiological and psychological changes that can worsen existing disabilities. Hormonal changes during this time may intensify spinal issues like scoliosis and lower the epileptogenic threshold. Individuals with multiple disabilities experience pain through the same mechanisms as others. In addition, we know that in very young children, but also in people with multiple disabilities, there is a deficit in the modulation of the nociceptive message. This is due to immature or damaged regulatory systems. There may also be a lack of cerebral integration of the meaning of their pain, making it more global and associated with a major anxiety component [26].

Pain is difficult to identify in children and adults with intellectual disabilities and/or communication difficulties. It is a subjective and personal experience, and the gold standard for describing and assessing pain is self-report. This is often not possible in people with intellectual disabilities or communication difficulties [27]. Identifying pain is made more difficult by the fact that differentiation can be difficult for children who are less able to compare with a previous state. This is also true for people with mild to moderate intellectual disabilities.

Pain Detection

The gaze directed at the person with multiple disabilities is the most powerful painkiller. How can we spot, how can we identify, how can we hear and consider the pain of a person who has so little connection? How can we accept the hypothesis of pain for others? And what are the prerequisites necessary for hearing what a person in pain, unable to speak, can tell us about their pain?

A person with multiple disabilities in pain must bring this word to others in search for relief. Indeed, in the case of a subject with multiple disabilities who has little or no access to verbal language, it is difficult to communicate their pain, its intensity, its duration, and its location. The etiologies of pains are often difficult to determine, due to the enormous number of pathologies linked to each other in the same subject [28]. Despite this, it is important to identify the pain expressed, to hear it, and to take care of it to avoid the establishment of a vicious circle and the installation of chronic pain. In the case of multiple disabilities, there is a possibility that "signs of the autistic spectrum is added from early childhood. In the past, it was common to say that people with autism were not sensitive to pain [29]. This idea was a major obstacle to listening to pain in autistic or very disabled people. However, it has been shown that these individuals do feel pain, and that they have a particular way of reacting to it.

When language is present, other complications can arise. The individual will be able to say that they are in pain, but due to their many deficits, such as disorders of tactile, sensory or deep sensitivity, the individual will find it difficult to express the location and description of their pain. This is particularly true in the case of hemi-asomatognosia, when it is possible to verbalize pain on the right, but on clinical examination we notice that the left side is much more inflamed. This does not mean that the right side is not painful, but it is essential not to dwell on this and to push the examination to the opposite side [30].

Behavioral and personality disorders can also impair pain recognition, as can intellectual disabilities. These results in a failure to develop a sense of envelope, difficulties in situating oneself in space and time, and disorders of reasoning and

memory acquisition. These disorders make it difficult to identify potential pain [31]. The expression of the sensory component of pain, i.e., the decoding of the nociceptive message in terms of intensity, duration, location, and quality of the stimulus, cannot be explored. However, an abnormal increase in behavioral disorders, stereotypies, or aggressive movements toward oneself or others may be a sign of underlying pain.

The most fundamental point, of course, is to "pay attention" as well as to "believe in the painful complaint" when it is present. Identifying pain involves this. It is necessary to look at the person, observe them, and examine them. This is especially true when you are dealing with someone who cannot speak or has limited communication skills [32]. This identification therefore involves observing and listening to the person with multiple disabilities. But then, what is listening? Listening means "being attentive to," in an attitude of vigilance and/or curiosity. It means listening to the other, therefore to the unknown, to what we do not know. We must observe the known and the unknown. Listening must be global, listening to the words but also to the body as a whole: gestures, gaze, facial expressions, attitudes, posture, tone, etc... All of this contributes to the expression of the subject's relationship to the world.

Listening also involves what is known, that is, oneself. When we listen to someone else, we compare their reactions to our own to make sense of them. However, having multiple disabilities strongly hinders this process of identification, which normally allows us to recognize ourselves in others. In these situations, we have no reliable basis on which to understand. The very act of trying to listen to patients, to observe them is taking a risk. It is taking the risk of making a mistake, but we must not stop listening. People with multiple disabilities allow us to see and hear their way of being in the world, and we must they have with the world, even if we sometimes make mistakes in our interpretations. We will never be able to represent or feel with certainty their sensations, their perceptions and their representations of the world, but we grasp fragments, words, and words.

The results of a study [33] show that it is possible to observe specific pain-related behavior items in a sufficiently reliable way in adults with PIMD in day-to-day situations. However, it is recommended that daily support professionals only score these items in everyday practice after sufficient training, in which calibration between observers should play an important role.

Pain Evaluation

To assess pain, consider:

- The family's opinion, the person's background, situations experienced, and trajectory.
- The person's disability.
- Medical history.
- Body signs (tension, posture, facial expressions, etc...).
- Individual characteristics (level of autonomy/mobility, bedridden, wheelchair-bound, etc....).
- The person's devices and technical aids (prostheses, orthoses, wheelchair, etc....).

Use a scale adapted to the individual, the situation, and the type of pain to determine a useful score [2]. Ensure that the same scale is used each time and by at least two "observers" who know the individual perfectly. Once the source of the pain is known, define the appropriate course of action and monitor the effectiveness of the treatment. For pressure ulcers, use risk scales and, in the case of pressure ulcers, assess the intensity of the pain during care [34]. Facilitate the transmission of information (temporality, intensity, location, type of pain) within the professional team and between the family and the facility. This information is collected by support staff (healthcare professionals, family), using assessment scales, and is stored in the "health" section of the personalized care plan for the person with multiple disabilities. Reassess pain regularly and at different times of the day, ideally using the same scale used for the first assessment (see the proposed "pain protocol" tool) [35]. Invite and help families to assess the pain of the person with multiple disabilities in their environment using the same tools, if possible. Look for the cause of the pain. Finding the origin should initially precedence over treating the pain.

Conclusion

Difficulty identifying and assessing pain and health problems contributes to the underdiagnosis of many medical conditions, leading to ongoing pain and discomfort. Ultimately, improving our understanding of pain can lead to better healthcare and help address the inequalities faced by people with multiple disabilities. The prevalence rate of chronic pain is high in adults with PIMD due to the elevated risk of medical conditions and procedures. Adults with PIMD must rely on their environment to observe whether they are experiencing pain. Therefore, it is crucial to have a reliable and valid pain observation instrument specifically designed for this target group. We believe this will enable earlier recognition and treatment of pain, and result in better quality of life for adults with PIMD.

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