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Rethinking Profound and Multiple Disabilities: A Challenge in Psychiatry

Michel Bourin[1,*]

[1]Neurobiology of Anxiety and Mood Disorders, Nantes University, 98 rue Joseph Blanchart, 44100 Nantes, France

[*]Correspondence should be addressed to Michel Bourin, michel.bourin@univ-nantes.fr

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Abstract

Defining profound intellectual disability remains a major clinical and conceptual challenge. Traditional approaches have sought criteria such as an estimated IQ below 20 or developmental-age equivalence under 24 or 36 months. However, these criteria are of limited utility when cognitive impairment is combined with severe motor, sensory, and health-related disabilities. In Francophone practice, the term polyhandicap describes individuals with a profound intellectual impairment and a severe motor disorder caused by the same cerebral dysfunction, resulting in extreme restrictions of autonomy, perception, expression, and relationships. In anglophone literature a parallel concept has emerged Profound Intellectual and Multiple Disabilities (PIMD). This editorial revisit the notion of polyhandicap/PIMD, highlights its clinical, familial, ethical and psychiatric implications, and argues for a multidisciplinary, human-centered approach. Recognizing the interdependence of impairments rather than their simple sum, the concept invites us to rethink autonomy, communication, relational capacity and dignity in populations often rendered invisible by conventional disability models. For psychiatry, polyhandicap prompts reflection on how we perceive personhood when speech is absent, autonomy minimal and cognition severely limited and how relational presence becomes therapeutic. By embracing this perspective, clinicians and researchers affirm that value and connection persist even in the most complex disabilities.

Keywords: Polyhandicap, Profound intellectual and multiple disabilities (PIMD), Ethics, Communication, Psychiatry

Introduction

Defining profound intellectual disability is far from straightforward. In many clinical and research contexts, the term refers to individuals with an estimated IQ below 20. Yet, in practice, such a measurement is more theoretical than measurable. Conventional psychometric tools lose validity at such levels of functioning, particularly when cognitive, sensory, and motor impairments coexist. Thus, some authors have instead proposed age-equivalent developmental criteria ranging from less than 12 to 36 months but even these benchmarks inadequately capture the lived complexity of individuals who combine deep cognitive impairment with multiple sensory, motor and health challenges [1].

The French Notion of "Polyhandicap"

In Francophone medicine, the concept of polyhandicap occupies a distinctive space. It describes a severe and complex condition resulting from a central nervous system injury that simultaneously affects intellectual and motor functions [2]. This dual impairment leads to profound limitations in autonomy, perception, communication and relational capacity. The "poly" in polyhandicap is not a mere accumulation of disabilities it denotes interacting disabilities that multiply rather than add up. The impairments reinforce one another, generating a unique and holistic clinical picture. Although the term polyhandicap has not gained wide international adoption, an almost identical concept emerged in the English-speaking world in the early 2000s under the acronym PIMD (Profound Intellectual and Multiple Disabilities). At the 2002 IASSID World Congress in Seattle, experts formally distinguished individuals with PIMD from those with cerebral palsy, recognizing the distinct combination of profound cognitive and motor disabilities [3].

A Clinical and Human Reality

PIMD represents one of the most complete forms of disability. It affects motor skills—often resulting in paralysis or severe

movement restriction; cognition with lack of verbal language and self-awareness; and perception—through the attenuation or loss of one or more senses. Individuals with polyhandicap typically depend entirely on others for activities of daily living. They often cannot walk, manipulate a wheelchair, or communicate through speech. Many experiences are epilepsy, orthopaedical deformities, digestive or respiratory complications, and frequent infections. Advances in genetics have clarified many of the previously "unknown causes". Today, prenatal cerebral insults, vascular accidents, congenital malformations, and infections such as cytomegalovirus (CMV) or human immunodeficiency virus (HIV) are well-documented contributors. Nevertheless, approximately one-third of cases remain of undetermined aetiologia, underlining the continuing need for genetic, neurodevelopmental and neuroimaging research [4].

The Family Perspective

For families, the presence of a person with PIMD transforms daily life. Continuous care is often required, including night-time monitoring for seizures or respiratory distress. One parent frequently reduces or abandons employment, while the other experiences indirect professional and emotional consequences. Respite care remains scarce and often costly due to the specificity of needs. Yet amid these constraints, many families describe a profound relational depth with their child or adult relative. The absence of language does not equal absence of communication. Subtle cues eye contact, breathing rhythms, micro-expressions, or body orientation create a non-verbal dialogue that requires attuned interpretation. When caregivers respond to these signals with consistency and empathy, genuine interaction and emotional reciprocity emerge [5].

Ethical and Psychiatric Implications

For psychiatry, PIMD represents more than a diagnostic challenge, it is a moral and epistemological test. How do we understand personhood in the absence of speech, autonomy, or measurable cognition? How do we recognize and respect an inner world that remains largely inaccessible through conventional clinical tools? The psychiatrist, neurologist, and developmental specialist are thus invited to shift from a model of deficit to one of presence to focus not solely on what is impaired, but on what persists: sensitivity, relational potential, emotional resonance [6]. In this sense, the study of polyhandicap blurs the boundaries between neurology, psychiatry and philosophy. It calls for a multidisciplinary, human-centered approach that includes medical management, rehabilitation, psychological support, and social inclusion.

Rethinking Value and Dignity

The reflection on polyhandicap also compels us to question dominant definitions of intelligence, autonomy, and quality of life. If we measure value only by productivity or independence, individuals with profound and multiple disabilities seem to exist outside the moral community. Yet their existence reminds us that vulnerability and dependence are intrinsic to human life. Clinically, this means shifting from a paradigm of normalization toward one of recognition of relational capacities, emotional expression, subjective experience, however subtle [7]. Ethically, it demands that psychiatry and society affirm the dignity of every human being, regardless of function or communication [8].

Conclusion

The concept of polyhandicap, though born in France, carries universal significance. It challenges clinicians and researchers to transcend categorical definitions and engage with the profound complexity of the human condition. For psychiatry, it offers a space to rediscover compassion as a clinical skill and relational presence as a form of therapeutic intervention. In an era dominated by precision medicine and genetic diagnosis, the lesson of polyhandicap is humility. We must remember that behind every classification lies a person one who, despite severe limitations, can still perceive, respond, and connect. To understand polyhandicap is to confront our own limits as clinicians and, ultimately, as human beings.

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