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Journal of Neuroscience and Neurological Surgery

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Mini Review

Genesis of Behavioral Disorders in people with Profound Intellectual and Multiple Disabilities

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Received date: March 06, 2025; **Accepted date:** March 20, 2025; **Published date:** March 26, 2025

Citation: Michel Bourin (2025), Genesis of Behavioral Disorders in people with Profound Intellectual and Multiple Disabilities, *J. Neuroscience and Neurological Surgery*, 17(3); **DOI:10.31579/2578-8868/365**

Abstract

Developmental disorders are characterized by a disruption in the normal development of intellectual or motor abilities (learning gestures). These developmental disorders can appear during pregnancy or after birth during the first months or years of the child's life. The causes are diverse (e.g. genetic factors, life events, etc.). In addition to communication and interaction difficulties, there are often everyday difficulties, sometimes extremely aggressive for those around them and which should not be underestimated: eating disorders (selectivity, refusal of pieces or certain foods, etc.) and sleep disorders (difficulty falling asleep and waking up at night) are very common. Mental retardation and epilepsy are frequently associated disorders (in 70% and 30% of cases respectively) that should be investigated. There is a lack of knowledge about participation of children with profound intellectual and multiple disabilities (PIMD) in family activities and how improved participation can be reached. Gathering such knowledge could enable an improvement in child functioning and wellbeing and also ease everyday life for families of a child with PIMD.

Keywords: behavioral disorders; behavioral phenotype; conduct problems; emotional symptoms; hyperactivity; peer problems

Introduction

Consensus conferences that include behavior alongside physical characteristics raise the issue of behavioral phenotypes and the inevitable interaction between environment and genes (1). Behaviors and genetic abnormalities were first combined into the concept of a behavioral phenotype in 1972 (2).

The term behavioral phenotype was used to refer to behaviors that are an integral part of certain genetic disorders, and the role of organic factors in the development of such behaviors was emphasized (3). However, since this definition was established, research on behavioral phenotypes has led to the use of a broader definition: "The increased likelihood or probability that individuals with a given syndrome will exhibit certain behavioral or developmental sequelae compared with those without the syndrome."

Theoretical models underlying the concept of behavioral phenotype.

They consist of the idea that genetic disorders do not have specific effects on behavior (specificity), each genetic disorder has one or more unique behavioral features (full specificity), and a few genetic disorders lead to only one outcome (partial specificity) (4). Partial specificity is probably the most common effect of genetic disorders of intellectual disability, because factors such as development, environment, and the rest of the individual's genome all affect behavior (5). The concept of partial specificity is particularly relevant to Angelman syndrome. In the consensus for Angelman syndrome, the four 100% consistent clinical features (developmental delay, speech disorders, movement disorders, and uniqueness of behavior) are also observed in individuals who do not have Angelman syndrome (6). Furthermore, in Angelman's early papers in 1965, the role of environment was acknowledged in his descriptions of three children. He reported that all three children had "easily elicited and prolonged paroxysms of laughter," a feature that has continued to be associated with Angelman syndrome (7)

Development of behavioral disorders in non-disabled children

The first three years of life represent the major period of motor, cognitive, emotional, interpersonal and attachment development. This development is influenced by genetic but also environmental factors and is carried out around key stages that serve as a reference for evaluation. It is artificially divided into four major areas: motor skills (gross and fine), speech and language, social interactions, performance and knowledge. Up to the age of 5, we speak of global developmental delay if at least two of the four aforementioned areas are affected (8). Early development is intense between birth and 18 months. It has a self-correcting and resilient tendency, which explains why early intervention can be very effective (9). However, we know that what is expressed early in terms of developmental disorders can have lasting consequences. Therefore, it is important not to be in a waiting attitude as soon as there is a clear deviation from the average in an important area of development. To assess a child's psychomotor development in consultation, it is first of all necessary to hear, if it exists, the parents' concerns and to listen to them. Their perception is essential and allows them, from the very first moments, to become actors in the intervention (10). The next step is to rigorously collect perinatal events (pregnancy, childbirth), history (particularly family) and early development history. The assessment continues with a careful and precise clinical examination, looking for possible warning signs, but also for elements that may be reassuring regarding the child's overall development (11). Any developmental delay in a child must be the subject of a multidisciplinary assessment. This involves carrying out a complete somatic assessment (in particular ENT, ophthalmological, neurological) and assessing the different areas of their development (communication and language, interactions, cognitive, sensory and motor domain, behavior, autonomy and schooling) and their environment. This involves specifying whether the delay is global or limited to a specific area of development, as may be the case in learning disorders.

The onset of problem behavior in the early years can set children on adverse developmental trajectories. This is particularly true for early externalizing behavior problems (i.e., hyperactivity, aggression), which can lead to persistent problems and poor academic performance (12). Boys and girls tend to exhibit different problem behaviors, with boys having higher rates of externalizing problems and, to some extent, more internalizing problems (withdrawal, depression) for girls (13).

Development of behavioral disorders in disabled children

Research has shown that children with disabilities are more likely than their nondisabled peers to exhibit behavior problems, including social and peer problems, conduct problems, oppositional behaviors, attention and hyperactivity difficulties, and internalizing problems. Yet we know little about the extent to which associations between disability and behavior are related to children's developmental stage and whether they attenuate or intensify by the time they enter school (14).

We know from decades of research that the early years are critical, when genes and environment, and the interaction between the two, trigger the development of brain structures that affect children for the rest of their lives. More broadly, children’s development up to age 3 provides the building blocks for increasingly complex social behaviors, emotional maturity, problem-solving skills and early literacy and numeracy skills that are essential for school entry (15). Literacy and numeracy are: ongoing, active processes that begin at birth and develop throughout life; essential for success in learning, daily life and participation in society; used to make decisions that affect our personal lives; the means by which students develop their knowledge and understanding in each subject or discipline; a responsibility shared by all educators from kindergarten to high school for each subject or discipline (16).

For some children, early behavior problems are temporary, resolved during the course of normal development, while for others they persist or even intensify during the early school years. School entry represents an expansion of children's developmental ecology from the primacy of parents and the home environment to include the school and peer context (17*)*. Whether the behavioral development of children with disabilities parallels that of their nondisabled peers in the early years following this transition to school is an important empirical undertaking, a better understanding of which will help determine the timing of interventions for children with disabilities.

Our current understanding of the association between disability and behavior is limited by a focus on specific impairments or conditions and the use of small, localized studies, both of which hinder generalizations. Disability encompasses long-term health problems, mental health problems, and sensory impairments, among others, allowing us to capture a broader range of disability conditions (18).

Using this measure enhances our understanding of the associations between disability, rather than specific impairments or conditions that may or may not be limiting, and behavior, enriching experiences in the home may help mitigate the development of behavior problems in young children with disabilities. On the other hand, given the increased levels of parental stress associated with parenting a young child with disabilities, less supportive home climates may exacerbate differences in behavior problems between children with and without disabilities (19). To our knowledge, despite the wealth of research testing the importance of the home environment on children's development and the ways in which it may mitigate socioeconomic disadvantage, research has not examined whether home environments promote greater convergence or divergence in behavioral trajectories between children with and without disabilities over time (20). The moderating role of parental warmth and harshness and the home learning environment on the behavioral trajectories of children with disabilities should be measured; particularly to better understand which aspects of parenting and the home environment mitigate or exacerbate which problem behaviors (21).

Four behavior problems appear to be the most relevant:

- *conduct problems,*
- *hyperactivity,*
- *peer problems*
- *emotional symptoms*

These different types of problem behaviors have been shown to be important for children's development, and they may present differently over time for children with and without disabilities (22). A large body of research attests to specific trajectories associated with the four types of childhood behavior problems (i.e., conduct problems, hyperactivity, peer problems, emotional symptoms), with preschool and early school years considered to be the time when most children learn early control over problem behaviors, particularly exclusionary behaviors (23). While conduct, hyperactivity, and peer problems generally decline during this period, emotional symptoms tend to be stable or increasing. The exception to this general trend is a small subset of children, including more boys than girls, who have high levels of physical aggression that persist (24). These studies, however, do not distinguish between children with and without disabilities. Studies that have explored the relationship between disability and behavior in the early years have shown that, compared with children without disabilities, children with disabilities experience more overall behavior problems, more severe and clinically significant problems, and more persistent problem behaviors, suggesting that the general declines reported for conduct, hyperactivity, and peer problems in the early school years may occur later or not at all for children with disabilities (25).

Additionally, a recent study found that children with disabilities were particularly susceptible to increased internalizing symptoms. Internalizing problems primarily include depression and anxiety. Symptoms of depression in older children include sadness, eating/weight problems, sleep disturbances, low energy, and low self-esteem (26). These findings are largely based on small, nonrepresentative cross-sectional samples and tend to focus on a particular type of impairment and more general problem behavior (rather than specific types). Exploring four behavioral trajectories across a representative sample of children allows us to assess how children with and without disabilities may respond differently to school entry (27). A large body of research has demonstrated that parenting characterized by high levels of warmth, cognitive stimulation, and clear limit setting is associated with favorable emotional and behavioral outcomes for children, with the opposite findings for parenting characterized by harsh, arbitrary discipline or emotional detachment (28). Parents can also provide materials and experiences in the home environment, such as reading and other learning activities, that promote children's early behavioral development.

Yet parenting a child with a disability can result in suboptimal parenting behaviors. Parents of children with disabilities experience higher levels of stress, more adjustment difficulties, and more conflict than other parents, which may lead to an increase in children's behavior problems over time, although these studies did not distinguish between types of problem behavior. Parents' ability to parent positively depends, in part, on their ability to recognize and interpret their children's behavior and emotional states, which can be difficult with children with disabilities (29). Some parents successfully adjust to having a child with a disability and are able to meet their special needs, while others face ongoing challenges to their parenting competence and confidence, becoming stuck in negative interaction patterns. Adverse parenting behaviors, such as lack of responsiveness, harsh discipline, and negative control, exacerbate externalizing and internalizing behavior problems in children with disabilities, while positive parenting behaviors may protect them from future developmental problems (30). A study found that the quality of the parent-child relationship was a better predictor of overall behavior problems in young children with disabilities at age 5. A better understanding of these nuances could help inform the timing and content of interventions to support families with children with disabilities (31).

Conclusion

There remains a need for broad and continued consideration of questions regarding mutual influence between the child, the family and the external personal assistant over time. In addition, questions about the factors which pull the child away from and towards the family must likewise be taken into account. Such awareness and knowledge about the impact of transactional regulations on participation and thus development would help in the identification and implementation of interventions, such as recommendations, for the child with PIMD and his or her family needs. The goal of such interventions is to better understand and improve child participation in the proximal processes of everyday life. Furthermore, an external personal assistant becomes a third party of the family unit and his or her role in relation to the child must thus be accompanied by discussions particularly regarding the assistant’s role as a support/relief for the family as a whole. Within such discussions, an understanding of and sensitivity to the family’s unique needs must be included to achieve the stability desired within their family system.

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DOI:10.31579/2578-8868/365