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## Behavioral Intervention and its outcome in intellectual disability

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### Abstract:

**Background:** Healthcare personnel may face diagnostic and management difficulties when dealing with the complicated but prevalent issue of challenging behavior in people with intellectual impairments. Although challenging behavior is typical with intellectual impairment, it may be challenging to detect and treat. It may harm the person's quality of life and need hospitalization. This article covered the complicated link between mental illness and the etiology of problematic behavior (including the nuanced connection to mental illness), diagnostic issues, the most recent research on psychosocial and pharmaceutical therapies, and service provision.

**Conclusion:** Positive behavioral support, a values-led and person-centered approach to behavioral treatments for decreasing problematic behavior, is gaining popularity. It is encouraging to think that evidence-based care for people with intellectual and developmental impairments and challenging behavior will improve as a result of the growing number of treatment options for this behavior and the ongoing development of research design, such as randomized controlled trials.

**Keywords:** Children with intellectual disability, behavioral intervention, Assessment of intellectual disabilities

### Introduction

Healthcare personnel may face diagnostic and management difficulties when dealing with the complicated but prevalent issue of challenging behavior in people with intellectual disabilities. All behavior has a reason to occur and is, therefore, the result of a person's relationship with their environment. A behavior must be seen as hazardous, frightful, disturbing, or annoying for it to be deemed challenging by another person. Challenging behavior is a socially created dynamic term. <sup>(1)</sup>

Since IQ tests are made to have dispersed normally with a median of 100 and a standard deviation of 15, on this premise alone, 2.3 % of the population would be predicted to have an IQ below 70. Studies estimate incidence rates varying from 3.31 to 156.03/per 1000 population, regarding a recent meta-analysis. <sup>(2)</sup>

The social milieu in which children with intellectual disability (ID) live and interact also affects their behavior. Families experience stress from having a kid with ID, and the child's behavioral

issues may add to that burden and frustrate parents and other caregivers. (3,4) A key concern in the total rehabilitation of patients with ID is managing behavioral issues. Behavior control is used with children with ID regardless of the kind of school special or regular). (5) This work was done to Review the literature on regard efficacy of different rehabilitation programs in children with ID.

**Overview of intellectual disability** A medical approach that employed terms like "feeble-minded," "mentally defective," "subnormal," and "retarded" to describe and develop the category of "intellectual impairment" in the past, developed into general insults as well as insults targeted especially at this group. The Eugenics movement, which led to the forced sterilization of tens of thousands of individuals with intellectual impairments and ultimately to Nazi experiments on them and their eradication, was the most severe proponent of the view that intellectually disabled persons are less worthy and subhuman. (6,7)

### **Nomenclature**

Intellectual disability or intellectual developmental disorder is utilized to define intellectual and adaptive performance that is substantially below the median as determined by individually managed, suitably normed, standardized, and validated tests of mental abilities and adaptive behavior, with onset throughout the developmental timeline from birth through adolescence. (8)

Abnormalities of intellectual growth are "a group of etiologically broad

parameters arising throughout the developmental period characterized by substantially below-average intellectual viability and adaptive attitude that is close to 2 or more standard deviations below the median (nearly less than the 2nd/3rd percentile)", according to the WHO. (9)

### **Epidemiology of intellectual disability**

During 2014–2016, the prevalence of children diagnosed with intellectual disability was 1.48% among boys and 0.90% among girls and was lower among younger children than older children: 0.73% among children aged 3–7 years, 1.45% among children aged 8–12 years, and 1.40% among children aged 13–17 years. (10)

### **Etiology of intellectual disability:**

Starting from a single cell as a zygote, the human embryo rapidly grows and differentiates into three layers. The brain develops from the outermost layer of the ectoderm; the other organs that develop from the ectoderm are the sense organs, other parts of the central and peripheral nervous system, the skin, and appendages, which are often affected in the presence of ID. (11,12)

The growth and maturation of the brain are under tight genetic control. However, the current trend is to transcend this dichotomy and think of the causes in a multi-factorial framework, where biomedical and psycho-social factors are considered important and often interacting. (12,13)

### **Prenatal causes:**

These are causes operative during the first and second trimester of pregnancy, especially during the first 12

weeks. These causes could be intrinsic to the embryo (i.e., embryonic/ genetic causes) or could be extrinsic (i.e., environmental) in origin. Most known causes of ID are prenatal and tend to produce delays in development that are noticeable from very early infancy. Most of these babies tend to improve with age, albeit at a slower pace. However, some genetic causes have an onset later and lead to progressive cognitive decline the so-called childhood onset neuro- degenerative disorders or progressive encephalopathies. Some examples are lysosomal storage disorders and adrenoleukodystrophy. <sup>(14,15)</sup>

- **Embryonic or genetic causes:** These are a group of disorders with either known or inferred genetic etiology. <sup>(16)</sup>
- **Prenatal maternal/ environmental:** These include deficiencies, infections, certain maternal diseases, exposure to toxins and teratogens, and substances such as alcohol and nicotine. These conditions are of importance because they are preventable. <sup>(17)</sup>

#### **Perinatal causes:**

These include causes that are operative from the third trimester of pregnancy to the neonatal period and can be further sub-classified into the following periods: <sup>(15)</sup>

- **Third-trimester complications:**
- There are many late pregnancy complications such as placenta previa, chronic infections, uncontrolled gestational diabetes, severe pre-eclampsia or eclampsia, and severe systemic diseases in the mother (e.g., cardiac problems, renal disease, etc.). These may adversely affect the dev-

elopment fetus, most often through placental dysfunction or deprivation of supply, and thereby affect brain development resulting in ID. <sup>(18)</sup>

- **Labor/ birth related:** Difficult and complicated labor such as prolonged second stage of labor, cord round the neck, premature rupture of membranes, abnormal presentations, and meconium aspiration can lead to severe asphyxia and result in hypoxic-ischemic encephalopathy (HIE). There may also be mechanical damage to the brain because of the inappropriate use of forceps. In addition, prematurity and low birth weight are also significant risk factors for developmental problems. <sup>(19,20)</sup>
- **Neonatal:** These include neonatal septicemia, severe hypoglycemia, and hyperbilirubinemia of any cause, and may put the baby at risk for ID. Rh isoimmunization leading to severe, prolonged hyperbilirubinemia and deposition of bile pigments in basal ganglia (kernicterus) can also lead to ID as well as dyskinetic cerebral palsy. <sup>(21,22)</sup>

#### **Postnatal causes:**

Causes operative beyond the neonatal period probably account for less than 10 % of ID and include infective encephalopathies (viral, bacterial, tuberculous) as well as traumatic brain injury. Severe, prolonged undernutrition and experiential deprivation are the two other factors that are known to be associated with impairments in cognitive development. <sup>(23,24)</sup>

#### **Incidence of etiological factors:**

In an earlier exhaustive review, McLaren and Bryson found that

chromosomal disorders were present in 4 – 8% of mild ID and 20 – 40% of more severe forms. Similarly, single gene disorders were responsible for 0 – 8% of mild ID and 5– 20% of more severe forms. Overall, etiology was unknown in up to 62% of mild ID and 40% of more severe forms.<sup>(25)</sup>

A recent study from Brazil found that around 40 % of cases were environmental in origin.<sup>(26)</sup> In contrast, a recent birth cohort study from Finland reported that in all cases of ID less than 15 % of etiology was attributable to environmental factors and around 35 % attributable to genetic causes.<sup>(27)</sup>

Etiology remains unknown in at least about a third of cases. This scenario could be changing, with more genetic causes being uncovered. A recent major review of the genetic basis of ID has reported that there has been an exponential increase in the diagnostic yield in moderate and severe ID in the last five years, and the yield in 2015 was around 60%.<sup>(28)</sup>

### **Genetics:**

The complex and intricate process of brain maturation is under tight genetic control. It is estimated that around One-third of the roughly 20,000 genes in the human genome are thought to be engaged in this approach.<sup>(29)</sup>

Some of these are more common, whereas most are rare in their occurrence, but as a group, they contribute to a large proportion of the occurrence of ID. The pathogenic changes in the human genome can be as small as a change in a single nucleotide or base pair (e.g., Hunter syndrome) or as big as the existence of an additional

chromosome (e.g., Down syndrome).<sup>(30)</sup>

### **Assessment of intellectual disability:**

The three components of ID—severe impairments in intellectual activity, major restrictions in adaptive behavior, and proof that the impairment began before the age of 18—are followed in the evaluation of ID. Assuming an expert, thorough, comprehensive examination with the use of suitable clinical judgment, the individual would have to: (1) score between 70 and 75 on a reliable standardized IQ test; (2) perform between the second and third percentile on a reliable test of standardized adaptive behavior, or around two SDs behind the mean; and (3) demonstrate the impairment before turning 18. It is crucial to conduct assessments of the existence (or lack) of ID with the greatest care and attention to all necessary procedures since there are significant stakes involved for the person, their family, and society.<sup>(31,32)</sup>

The evaluation of ID may be made more difficult by several occurrences. First, the evaluation can take place after the individual reached adulthood, which raises the issue of whether the handicap started before the person turned 18. With great consideration to complete recording of the three components of the definition gathered from history (social, health, and academic), as well as present evaluation, a "retrospective" diagnosis may be made. Second, occasionally the tests employed were no longer valid or had out-of-date standards, rendering the outcomes invalid. This "Flynn Effect" renders

results invalid and necessitates an adjustment depending on the age of the standards.<sup>(33)</sup>

Third, sometimes the evaluator lacks the clinical reasoning abilities or attitudes required to deliver a reliable evaluation in ID. A unique kind of judgment based on regard for the individual is referred to as clinical judgment. Clinical reasoning results from the clinician's specific education and experience, in-depth familiarity with the patient and his or her environs, analysis of large amounts of data, and application of critical thinking abilities.<sup>(34,35)</sup>

A team of specialists is needed for the screening and evaluation of children who have an ID or who are at risk of developing it due to the potential difficulties across developmental domains. In general, the team recognizes both advantages and problems in adaptive functions and determines necessary supports across the conceptual, practical, and social domains for learning. The team members will depend on the unique requirements of the kid. Families are essential members of the evaluation team because they provide vital and distinctive information about the qualities, weaknesses, and needs of their children. They are aware of the typical daily routines, comprehend their children's communication requirements, and place a high emphasis on outcomes that promote their children's health, safety, independence, and formation of enduring connections.<sup>(36)</sup>

There will probably be official and informal methods of evaluation. To diagnose an ID and establish a child's eligibility for treatment, further formal

testing is necessary. To determine a child's relative advantages, developmental milestone accomplishments, and limits across multiple developmental areas, more informal testing is employed. This often entails eliciting play activities, parent informant measurements, parent interviews, and observations of the kid in various circumstances. Regardless of a child's age or level of development, a thorough evaluation should be carried out and include the following components:<sup>(37)</sup>

examination of the child's medical, educational, and living situation; assessments of the child's vocalizations, gesture use, speech sound and production of words, language skills, and use of indications and pictures to communicate, as well as hearing, vision, motor, and cognitive tests, assessments of independent play and play with peers, observations of activities and social communication with peers and adults, and assessments of receptive and expressive language involving an evaluation of the child's oral motor and swallowing abilities as well as listening, speaking, reading, and writing.<sup>(37)</sup>

Also, as part of the clinical assessment of intellectual impairment, it is crucial to detect the behavioral manifestations of co-morbid diseases. When compared to children and adolescents without intellectual impairment, people with intellectual disability have a 3–4 times greater risk of having additional linked mental health issues.<sup>(38)</sup>

### **Evaluation**

The child's age upon presentation, the intensity of the symptoms, and the necessity to seek a causative identification

will all be taken into consideration when determining the breadth and depth of an examination of kids and teens for intellectual impairment. Clinical examination, psychiatric testing, genetic and metabolic tests, and imaging procedures are all included in this kind of study.<sup>(39)</sup>

Formal assessments of intellectual and adaptive functioning can be administered and interpreted in many different ways; as a result, The child's age and developmental status (mental age), education level, environmental factors, and social and cultural background should all be included in these evaluations. For all kids and teenagers with intellectual disabilities, a complete audiological and visual examination should be part of the workup.<sup>(40)</sup>

To assure the validity of the findings, the psychologist doing the evaluations should have experience with valid and accurate evaluation processes. For proper diagnosis of severity levels, the psychologist should have significant expertise in dealing with people who have intellectual disabilities. It is crucial to take into account how social class, stigma, and gender affect intellectual functioning.<sup>(41,42)</sup>

A clinical geneticist or biochemical geneticist should be consulted before doing any genetic or metabolic testing, to offer pre- and post-testing genetic counseling to families. Between 2 and 7% of genetic tests successfully identify a particular hereditary disease.<sup>(43)</sup>

The probability of aberrant neuroimaging findings in people with intellectual disabilities ranges from 33 to 63%. However, aberrant results on

neuroimaging may or may not aid in identifying a cause of intellectual impairment. Multiple abnormalities have been discovered on MRI of the brain in people with intellectual disabilities.<sup>(39)</sup>

In most cases, the initial test for children and adolescents whose intellectual impairment is unknown is the chromosomal microarray (CMA) is advised. According to studies, CMA can identify a particular genetic etiology in 12% of all individuals with ID.<sup>(8)</sup>

### Rehabilitation and its outcome

Children's chances to maximize their developmental potential and efficiency, as well as their quality of life and social involvement, is improved by early diagnosis of children with developmental disorders and early childhood intervention (ECI).<sup>(44)</sup>

Early identifying and intervention are two separate but complementary strands; prompt identifying of children with developmental disabilities is necessary for early intervention, which supports the cumulative process of development by assisting kids in picking up new skills and behaviors that will support and strengthen learning. Additionally, certain ECIs may have broader advantages for caregivers, such as building support and assisting in the development of their knowledge, confidence, and coping mechanisms, all of which may have a favorable effect on their mental health.<sup>(45,46)</sup>

I may include a variety of integrated multidisciplinary services and take many different forms, such as a hospital or clinic-based treatment, school-based programs, parental and commu-

nity assistance, and home-based childcare therapies.<sup>(46)</sup>

Family-centered treatments are more likely in high-resource settings to provide the highest satisfaction with services and enhance the psychological wellbeing of the child and caregiver.<sup>(47)</sup>

Caregiver Skills Training (CST) has been established by the WHO for those who look after children with intellectual disabilities. 9 group meetings and 3 home visits make up the CST. The course covers approaches to handling difficult behaviors and encourages dialogue and learning.<sup>(48)</sup>

The limited integration of the group format by lay facilitators into health systems, however, continues to pose a hurdle to its sustainable and scalable quality delivery. Although there is currently a lack of evidence supporting their efficacy, randomized controlled trials are currently being conducted in Pakistan (Family Networks [FaNs] for Children with Developmental Abnormalities and Delays) and Italy, with additional trials scheduled for China, Ethiopia, and Kenya in the future.<sup>(49,50)</sup>

Learning through Everyday Activities with Parents (LEAP-CP) is a family-centered intervention delivered peer to peer at home for 30 weeks 2h visits that aim to improve the mobility of children with cerebral palsy.<sup>(51)</sup>

Under the "Ubuntu" banner, the London School of Hygiene & Tropical Medicine (UK) has created three caregiver group programs. The treatments last for ten sessions and include topics including eating, posture, communi-

cation, and play. The information is provided in the form of a neighborhood support group. The Resource "Getting to Know Cerebral Palsy" was created as a means of empowering families via a community-based participatory approach.<sup>(52)</sup>

The ABAaNA ('Abaana', meaning 'children' in the local language Luganda) Early Intervention Program (EIP) was created in response to a recognized need to assist families of infants and toddlers (<2 years) with developing disabilities.<sup>(53)</sup>

"Juntos" (means together in Portuguese and Spanish) was created for families in Latin America with children who have the congenital Zika condition and has a heightened focus on caregiver emotional wellbeing, which is undoubtedly essential to a child's early development.<sup>(54,55)</sup>

One of the therapies offered for children with ASD is a parent-mediated intervention in South Asia (PASS) in Pakistan and India. The intervention was modified so that non-specialist personnel could give it and included video feedback techniques to address parent-child interaction. Since PASS aims to improve a child's social communication, it will be crucial to include common mental health comorbidities like sleep issues in larger intervention programs.<sup>(56)</sup>

By changing developmental trajectories and eliminating cascading problems, early intervention may improve the development of young children with ID. There is a large, ideal window for the delivery of early intervention because many IDs causing problems

are discovered early in life, during pregnancy, or at birth.<sup>(57)</sup>

The science of applied behavior analysis (ABA) serves as the foundation for behavioral therapies. They both hold the belief that a person learns and maintains a behavior via its antecedents and consequences (i.e., observed environmental occurrences). It is utilized to address socially significant conduct. The development of new abilities and a repertoire that reduces problematic behavior involves the systematic application of consequences as well as the modification of antecedent factors (such as establishing operations and discriminative stimuli).<sup>(58)</sup>

In contrast, there hasn't been a lot of thorough study on the benefits of early behavioral therapies for young ID children. The interventions aim to develop appropriate social, communication, and behavioral skills that enable the individual to replace the problem behavior with a functionally equivalent behavior that is more appropriate. It avoids the use of aversive measures such as punishment (e.g., excluding the individual from certain activities) and promotes the use of positive and supportive strategies.<sup>(59)</sup>

A review of 109 articles evaluating positive behavioral support interventions concluded that 52% of interventions reduced challenging behavior by at least 90% from baseline levels and 68% by at least 80%. For about two-thirds of the interventions, the effect was maintained for between 1 and 24 months. Evidence was also found regarding factors that influence efficacy: interventions were more effective for

single than for combinations of behaviors and when they were implemented by the individual's regular caregivers as opposed to external specialist providers.<sup>(59,60)</sup>

### **Techniques for Early Behavioral Intervention**

#### **Focused and Comprehensive**

Focused and comprehensive behavioral therapies fall into two categories. Focused treatments aim to bring about certain behavioral or developmental results. The use of discrete-trial instruction, reinforcement, and prompting are a few examples of targeted treatments. These treatments are employed for a brief time to show that a certain targeted behavior has changed.<sup>(61)</sup>

These applications' major objectives, however, have not been the acquisition of abilities in a wide range of subjects, but rather the management of troublesome behaviors. Recent reviews have focused on the usage of focused ABA interventions for people with fragile X disorder, fetal alcohol spectrum disorder, and other neurogenetic abnormalities. They have also highlighted the value of focused ABA interventions for teaching interaction to individuals with Down disorder and for students with IDD in special education.<sup>(62,63)</sup>

Various evaluations indicate that targeted ABA therapies frequently lead to improvements in targeted behavior in these populations, but they also draw attention to the paucity of studies that specifically address the requirements of ID subgroups. Focused ABA treatments are often utilized for behavior management throughout the spectrum,



but they do not address other crucial areas of need. Numerous writers advocate for expanding the use of targeted ABA therapies in groups other than those with ASD.<sup>(64,65)</sup>

With just a few cases focusing on the behavior of other subgroups including Angelman disorder, Williams' disorder, and Prader-Willi disorder, the study is even more scarce for other diseases.<sup>(66)</sup>

Comprehensive treatments, in contrast to targeted interventions, are a collection of techniques intended to have a wider developmental influence on intellectual and developmental delay's (IDD) primary need areas. These treatments last for a long time (a year or more), are vigorous (25 hours per week, for example), and include a variety of targeted ABA techniques including modeling, prompting, chaining, and direct teaching.<sup>(67)</sup>

The use of early intensive behavioral intervention (EIBI), which has received the most study and is often used with young children with ASD and concomitant intellectual impairment, has been supported by several studies. Substantial improvements in cognitive and adaptive performance as well as a lessening of the intensity of ASD symptoms have all been associated with it.<sup>(68)</sup>

Young children with IDD have benefited somewhat from milieu teaching methods and their numerous iterations in terms of modifications to their language and social interaction. Significant long-term repercussions on children's communicative behavior have been discovered through enhanced

milieu teaching (EMT) research. After a year of parent-implemented EMT for preschool children with IDD (including DS and ASD), Kaiser and Roberts observed substantial long-term impacts on the children's communicative behavior.<sup>(69)</sup>

Few studies have specifically examined milieu communication teaching (MCT) as applied to young children with IDD, and further study is required to determine the effectiveness of the different iterations. Recent MCT research has started to investigate the impact of intervention intensity and the variations in results for different subgroups.<sup>(70)</sup>

There is limited research that identifies the impacts of MCT's cumulative treatment intensity on children with IDD, but there is rising evidence that a person's play abilities and etiology may help treatment outcomes.<sup>(71)</sup>

### Parent Training

Parent training techniques have been taken from the research on disruptive behavior disorders and used on young children with IDD because of the important role that parents play in their child's life. Supporting parents of kids with IDD helps families thrive, promotes parent mental health, and lowers the chance of subsequent problem behavior.<sup>(72)</sup>

For use with parents of preschoolers with IDD of mixed etiology, McIntyre adapted Webster-Incredible Stratton's Years Parent Training (IYPT), an evidence-based parent training program. The usefulness of many behavioral parents' training strategies in addressing

problematic behavior in young children with IDD has been experimentally confirmed (IYPT-DD).<sup>(73)</sup>

### Conclusion

There is growing interest in behavioral therapies, such as positive behavioral support, a values-driven, and person-centered strategy, for lowering problematic behavior. It is encouraging to think that evidence-based care for people with intellectual and developmental disabilities and challenging behavior will improve as a result of the growing number of treatment options for this behavior and the ongoing development of study design, including randomized controlled trials.

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