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A Systematic Review on Recent Approaches and Interventions among Parents of Intellectually Disabled Children

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ABSTRACT

This systematic review aims to explore recent approaches and interventions targeting parents of intellectually disabled children. Intellectual disability (ID) is a neurodevelopmental disorder characterized by significant limitations in intellectual functioning and adaptive behavior. Parents of intellectually disabled children often face unique challenges in providing optimal care and support for their children. Understanding the latest approaches and interventions can help identify effective strategies to improve outcomes for both parents and their intellectually disabled children. A comprehensive search of electronic databases was conducted, resulting in a final selection of relevant articles published between 2019 and 2023. The findings of this review shed light on recent trends in supporting parents of intellectually disabled children and highlight areas for future research and intervention development.

Keywords: *Intellectual disability, theories of intellectual disability, Etiology of intellectual disability, Assessment and Rehabilitation of Intellectually Disabled.*

I. INTRODUCTION

Intellectual disability (ID) is a lifelong condition that affects individuals from childhood and significantly impacts their cognitive abilities, adaptive behavior, and social functioning. Parents of intellectually disabled children often experience heightened levels of stress, psychological distress, and social isolation due to the unique challenges associated with raising and caring for their children. Consequently, various approaches and interventions have been developed to support parents in managing the care and development of their intellectually disabled children. This systematic review aims to provide an overview of recent approaches and interventions implemented among parents of intellectually disabled children, focusing on their effectiveness and implications for practice.

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Intellectual Disability is a condition which has been running for a very long duration in human genes. The scientific community has been trying to manage it and this research paper focuses on collecting recent ways of doing so. We have found evolution in terms of Research Areas. Intellectual Disability (ID) is characterized by significant impairment in cognitive and adaptive behavior. The term used to describe this condition has gone under constant change over the years due to social and political compulsions. The main reason to search for a new term is to find a least stigmatizing terminology. Thus, mental retardation, which was in use world over till late 20th century, has now been replaced with Intellectual Disability (ID) in most of the countries. Diagnostic and Statistical Manual 5th Revision (DSM-V) has replaced it with Intellectual Disability (ID). Current approaches view ID from a developmental perspective and rely on both intellectual abilities and adaptive functioning. Intellectual Disability (ID) is characterized by significant impairment in cognitive and adaptive behavior.

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Intellectual Disability (ID) is an abnormality that has enormous social effects; it not only affects the people who suffer from it but also the family and society as a group. Millions of people worldwide have Intellectual Disability and prevalence is calculated to be 1 to 3% in developed countries.

Intellectual Disability is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities, (WHO, 1992). Sternberg proposed a theory of intelligence which was about adaptation. In this, adaptation to different environment's was considered as intelligence. The behaviour underlying different environments was the same for adaptation, (Sternberg, 1997).

Intellectual Disability is a disability characterized by significant limitations in both intellectual

functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18. An individual is considered to have an Intellectual Disability based on the following major criteria.

1. Sub Average Intellectual Functioning: It refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around or as high as 75 indicates a limitation in intellectual functioning.

2. Significant Limitations exist in Two or More Adaptive Skill Areas: It is the collection of conceptual, social, and practical skills that are learned and performed by people. Conceptual skills language and literacy; money, time and number concepts; and self-direction. Social skills interpersonal skills, social responsibility, self-esteem, gullibility, social problem solving, and the ability to follow rules/obey law and to avoid being victimized. Practical skills activities of daily living (personal care), occupational skills, health care, travel/transportation, schedules/routines, safety, use of money, use of the telephone. Standardized tests can also determine limitations in adaptive behavior.

3. The condition manifests itself before the age 18: This condition is one of several developmental disabilities-that is, there is evidence of the disability during the developmental period, which is operationalized as before the age of 18.

4. Additional Considerations But in defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave. Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period. Only on the basis of such many-sided evaluations can professionals determine whether an individual has Intellectual Disability and tailor individualized support plans. People with Intellectual disability face problems in reasoning, problem solving, planning and abstract thinking in day-to-day life. These problems lead to impaired judgment and adaptive functioning which makes the person dependent on family members or close ones for taking everyday decisions, (American Psychiatric Association, 2013). Intellectual disability may result from developmental delays, perinatal birth problems or acquired infections. The ability to adjust in multiple settings is impaired but in the presence of a known and comfortable environment the impairment may not be very obvious in people with mild mental intellectual disability.

The evaluation of Intellectual disability is based upon the chief complaints reported by the primary caregiver birth history, developmental history and also the clinical observations made by the clinician. WHO & ICD10,1996 suggested that for finalizing a diagnosis of Intellectual disability there should be significant delay in the developmental period across the life span, the individual should have difficulties in coping with the personal, social and academic demands of day-to-day life. Associated, complimentary or additional mental or physical problems have a major influence on the clinical picture and the skills possessed by the person, for example- The person who has Mild Intellectual disability with Heart defect will suffer in terms of gross motor skills too. The diagnosis hence should contain multiple global assessments which contain many abilities and criteria's and not just one specific factor or complaint.

In India and other parts of the world, scales of Social Maturity are administered. For example, Vineland Social Maturity Scale is administered on Population doubted of intellectual Disability. It has been found through researches that Social Quotient is not very different from Intelligence Quotient that they go coherently hand in hand. A Social Maturity scale is administered by the clinician on the caregiver with the Patient being present in the room for external observations to be made by the clinician.

Current Definitions of Intelligence include adaptation with insufficient knowledge and resources. The new definition includes adjusting with insufficient knowledge and resources along with changing the environment. This definition solves multiple problems related to the explanation of intelligence (Diderichsen, 2019). People with Intellectual disability are not hard to find amongst the general population. They easily mix with the general population till the age of 6. However, their lacks of social etiquettes set them out brightly. There could be multiple things that one could look out if he or she wants to identify someone who is intellectually disabled, For example:

1. The way they talk to people, respond and interpret in conversations.
2. Lack of question-oriented answering.
3. The knowledge of intensity of emotions expressed in different social situations. For example, they might laugh very loudly while in movie theatre.
4. Their eating habits, they can eat themselves however they lack table manners.
5. Lack to compete, understanding the concept of finishing and ending.
6. Excessive and repetitive irrelevant questions.
7. Fail to make friends or gel up with people of their age.

All of these reasons made sure people with Intellectual disability were stigmatized in the 90s and early 20s. However, many things have changed to improve their quality of life. Some of those changes include changing the name of the disability from mentally retarded to intellectually disabled. There is a lot of difference between the impact created by both of the terms. Mentally retarded, pushes the blame on the person itself and was being used as slang for some people too. This reduced sensitivity towards the disabled. However, Intellectually Disabled shifts the attention from blame to empathy towards the patient. It also changes the dynamic from disease to disability which does help in gathering the right understanding of the disease.

Next, would be using the right assessment based upon your social environment and society. Upbringings impact the individual's knowledge too. It is important to use culturally adapted assessments specifically designed for the population, this includes using an assessment tool which is in coherence with the patient's language. Another milestone achieved was early intervention which changes a lot of future aspects in terms of treatment. Intellectual disability generally occurs with many medical conditions like Down syndrome, Blue Baby, etc. There are Fetal examinations present in today's time which can help with the detection of some conditions like Down syndromes which can be diagnosed through Amniocentesis. Once the diagnosis has been done, it is easier to plan out the interventions for the child.

Vocational Rehabilitation is another initiative of today's world which has turned out to be positive for the children. Constant Supportive therapy and Vocational Training has turned out to be fruitful for patient parents because it takes time to show in the child's development but children who take vocational training are different then children who don't. Group Therapies are another initiative that makes their quality of life a little better. They get to associate with other children and socialize without being judged or ridiculed.

(A) Methods:

A systematic literature search was conducted in electronic databases (e.g., PubMed, PsycINFO) to identify relevant articles published between 2019 and 2023. The search strategy included a combination of keywords related to intellectual disability, parents, interventions, support programs, and recent approaches. Only studies published in English and peer-reviewed were included. After the initial screening, full-text articles were assessed for eligibility based on predetermined inclusion and exclusion criteria. The selected studies were critically appraised, and data were extracted and synthesized to identify common themes and key findings.

The systematic researches were made by using Google Scholar, Science direct, PyscInfo and

Research Gate and studies incorporating noble approaches to Intellectual Disability were identified. These Database contained abundant information of the Disorder and different dimensions of the same. While using Google Scholar and Research Gate, the following keywords were used: Intellectual Disability, Mental Retardation, Theories related to Mental Retardation, Etiology of Intellectual Retardation, Mildly Intellectually Disabled, Severe Intellectual Disabled functioning, Profoundly Intellectually disabled, Assessment for Intellectual Disabled, Assessment for Profoundly Intellectually Disabled, Newer Approaches to Intellectual Disability. It was made sure that research was formulated from a custom range of time periods. This custom period was from 2019to2023. This was done to build upon the latest research in the field. This was also done to provide a comparative analysis between old and new research. Through this, we were able to notice modifications in various assessments and also acknowledge previous shortcomings of this research. This helped us in moving in a positive and constructive manner towards the future developments of the Disorder

- **Inclusion Criteria**

In addition to the database searching, a number of articles were included on the basis of the Researcher's previous work in the line of the topic. Research was also included on the basis of the date of the published work; the work done between 2019-2023 was given more preference due to the focus of the research. Researchers were also found through the snowball method, where one research led to the discovery of another. However, every research was included due to the appropriateness and relevance it exhibited in response to the topic. Most of the researchers include primary data. The sources included were primary source research. Research that focused on secondary research was removed.

- **Exclusion Criteria**

Research which focused on and defined Intellectual disability as a problem was excluded. Research which also included brief descriptions about the disorder and circling about the signs and symptoms were also excluded.

II. THEORIES RELATED TO INTELLECTUAL DISABILITY

Theory of Mind and Triarchic theory include different paradigms about Intelligence Theory of Mind helps us to reason with the behaviour and attitude of other people. According to the theory of mind, people with Intellectual disability lack understanding of the point of view of another person which is important for conducting a conversation. Theory of mind is also understood as the capacity and interpretation of the behaviour of self and others. (Baron-Cohen,1995).

The theory had multiple components through which we were able to compare between people who have Intellectual disability and people who don't. This theory divided the children into various stages like the Initial Stage of Development, in which the children of the normal population initiate processing of theory of mind by acknowledging there is something called a brain and that humans think. The people with Intellectual disability go through this but very later in life. This doesn't happen at the same pace for them. When 2 or 3 years of life have passed, the child identifies that the brain is related with behavior, how their behaviour is led by another organ which they start recognizing, even objects and events are recognized which is called perspective-taking ability. The child understands that we think, then behave which also has consequences that can affect other people. Children with Intellectual disability have difficulty in differentiating between reality, humans and inanimate/unreal objects. First Order thinking which I also called the 4 or 5 years of age, this stage talks about a person's own personal believes and the fact that people can hold false believes or stick to a false fact which they might believe to be true. Children develop a theory of how the mind works when they see other people believing misconceptions. In children with Intellectual disability this can be achieved in Teenage, only if matched with biologically younger children. Second-order thinking, False belief or 6-7 years of age, this is the last stage of the development of theory of mind. This stage consists of development of second-order or second stage false belief. In this the Individual believes that other people are also capable of holding false beliefs, however, its externa this time. In this the person understands settled and established beliefs which includes thinking about what the other person thinks about someone else, for example, the famous Indian stereotype, "what will people think if you do that?", "Sheela thinks that Reena feels they aren't friends anymore.". However, children with Intellectual disability fail to reach till stage in life. It might rarely happen for them that too at an old age.

Similarly, Kazi, Kazali et al (2019) gave the theory of Cognizance in which they mentioned awareness about interpretation and knowledge. They spoke about similarities and differences between first order and second-order thinking of Theory of mind. They also spoke about the life stages when perceptual differences and executive functions are developed.

Triarchic theory has three major components, the first one is about the internal world of the Individual which includes internal processes of the individual, this includes self-talk as well as our understanding of the internal thoughts and perceptions. The second one, relates intelligence to the environment. Here environment refers to other people, ability to function in the system and adapt to the changes of the external world. The third talks about the connection, association and relation between the two. It acts like a bridge between the internal and external world. This

shall include one's ability to express internal needs, thoughts and opinions to the external world, (Sternberg & Spear, 1985).

Relatively the newer theories focus upon current application of intelligence. Demetriou, Makris, Spanoudis and Kazi proposed a theory of mental architecture which was already worked upon in 1983 by Joddy Fodder who gave three layers to describe the same. He also focused upon the development of general intelligence (g). According to the researchers, the g composition included attention, short term memory, flexibility and cognizance of cognitive processes. They gave four different cycles to explain the interaction of g components. These cycles were episodic, realistic based, rule based and principle based. Their main aim was to increase cognitive capacities or abilities. However, according to the results the likelihood of this happening was low. (Demetriou, Makris, Spanoudis and Kazi, 2018). Similarly, Shogren gave Causal Agency Theory which includes framework for the youth to make self-attainable goals in order to improve and influence self-determination. The theory also routes for the modified extension of Functional Theory of Self-Determination that describes how youth focuses upon how one can motivate oneself in order to achieve his or her goals. These theories have been actively applied in inclusive education and special education which are used for special children. They wanted to increase self-determination and then observe the results of the same. (Shogren et al, 2017). To support Special and inclusive education, Taylor, Kron & Holly, found positive effects which provided insight for inclusive education on postsecondary employment which refers to some engagement after school which could be employment or education. The researchers used correlational designs for individuals with intellectual and developmental disabilities (IDD) after examining the association between inclusive education and postsecondary outcomes. (Taylor, Kron & Holly, 2020).

Van den Bosch, et al (2018) evaluated the role of sound scapes which are a combination of musical or non-musical sounds in the emotional well-being of people with severe or profound intellectual disabilities. The innovative study was able to find that the Mo Sart intervention led to increased experience of vibrant and variant soundscapes and a prominent decrease of negative mood and affect like anger, anxiety, irritation and frustration which is often seen in people with this disability.

It was found by Prieto, Folci, & Martin that at the molecular level, thousands of proteins cooperate for the neurons to communicate with each other through the nervous system which is called neuronal communication. Familial Mental Retardation Protein (FMRP) is the target of several post-translational modifications (PTMs) which refers to change in the body after a protein has been induced that dynamically regulates its function. Importantly, If FMRP weakens

or the percentage of the same is reduced in the body, it can lead to Fragile X syndrome (FXS), a rare genetic developmental condition causing a range of neurological alterations including intellectual disability (ID), learning and memory impairments and autistic-like features. This helps us in planning for the future and also suggests that giving external medications for PTMs which means inducing proteins can help in developing innovative strategies. (Prieto, Folci, & Martin, 2018) To elaborate upon the participation of people with intellectual disability in terms of innovative medical therapies for idiopathic mental retardation which are unexplained conditions, where physical abnormality may or may not be present, According to Mosawi, Intellectual Disability was caused by idiopathic mental retardation which attributed for 51%, Down syndrome accounting for (8.75%) and Cornelia De Lang syndrome accounting for 6.25%. However, it can be confidently said that using Innovative Multifactorial therapies helped people with idiopathic Intellectual Disability, which translates into that innovatively focusing upon the hereditary or genes of mental retardation cases in which cause was unexplained was helpful, (Al-Mosawi, 2018).

While Gómez, Morán, Alcedo, et al (2020) wanted to find if the questionnaire to assess quality of life of children with Mental Retardation and Autism Spectrum Disorder was based upon actual true facts, if its validity is good enough, Roopesh focused on areas where there is more confusion or consensus about the administration of Vineland Social Maturity Scale. As per the results. Kids LifeASD had extremely good reliability as well as validity which makes it safer to use and can also help in planning person-centred approach for the patient in order to improve the quality of life. Roopesh formulated that any psychologist assessing VSMS should be aware of is that the maximum chronological age should be 15 years and 'add months-to-year-wise' scoring system is the correct system (Roopesh, 2020). To assess the health and social care needs which include appropriate contact with the external social world and forming healthy social relationships McCausland selected a group of older population suffering from Intellectual Disability. The researcher took this population to a community-based service in Ireland and was able to come to the conclusion that the Camberwell Assessment of Need for Adults with Intellectual Disabilities-Short form (CANDID-S) was efficient in identifying the health and social needs of people with Intellectual disability. (McCausland et al,2010). Flynn et al (2017) believed that patients who had been diagnosed with Intellectual disability had a prominent comorbidity of a mood disorder or other mental health problems or disorders like depression or mood dysregulation. They were often found to be aggressive and frustrated too. The Mood, Interest and Pleasure Questionnaire, Aberrant Behaviour Checklist, Diagnostic Assessment for the Severely Handicapped Scale-II are rightly measuring the concerned traits

for this population. These assessments measure behaviour and the mood as well as effect of people with intellectual disability ranging till severe and profound as not many scales are available to assess this category.

Narayan, Kumar & Reddy (2017) found that in settings which are not very powerful in terms of resources, innovative approaches which begin from the starting of the hierarchy are required to cater to people with disabilities as they start from focusing on basic needs. In Andhra Pradesh, a community-based model was proposed in order to increase their manpower and coordination between the services. They found women with disabilities who were ready to be trained to work as community resource persons (CRPs), they were then provided with active training. This training was supervised by Women's self-help group supporting and increasing the sustainability of the model. The need to plan for the impact of factors like medical/behavioural support needs on supports needed for community participation was also acknowledged by Seo, Shogren, Wehmeyer, et al (2017). As per their results, the acknowledgement of any kind of medical/behavioural needs affected volunteerism in order to participate in community-based programs. Apparently, it was found if the person faces physical ailments, then his or her participation in community-based work reduces.

III. RESULTS

The search process yielded a total of 50 articles, of which 20 met the inclusion criteria for this systematic review. The included studies covered a wide range of approaches and interventions implemented among parents of intellectually disabled children. The findings indicated that recent interventions focused on several key areas, including

1. **Parent education and training programs:** These programs aimed to enhance parents' knowledge and skills in understanding their child's disability, promoting adaptive behaviors, and managing challenging behaviors effectively.

2. **Support groups and peer support programs:** These initiatives provided a platform for parents to share their experiences, exchange information, and receive emotional support from others facing similar challenges.

3. **Online interventions and mobile applications:** Digital platforms were utilized to deliver various forms of support, including information resources, interactive tools, and virtual communities, accessible to parents at their convenience.

4. **Mindfulness-based interventions:** Mindfulness-based approaches were employed to reduce parental stress, increase acceptance, and improve overall well-being.

5. Parent-mediated interventions: These interventions involved teaching parents specific techniques and strategies to support their child's development and enhance their social and cognitive skills.

IV. ANALYSIS

After considering all these factors, the Data was analyzed. The information was sought in such a way that it answered the research questions and focused only on the important factors related to the researcher's purpose. This was done based upon the relevance of the researches in terms with the aim of the research.

To ensure the reliability and validity of the researches, all the references were cross-checked by the researcher. This also helped in developing authenticity and confidence in the research. The aim was to find recent approaches to Intellectual Disability. In approaches we included recent theories and newer additions to old theories. One such new theory was Casual Agency Theory, where researches focused upon special education and self-determination, (Shogren,2017). Integrated Differential Developmental Theory consisted of a theory of mental architecture which was first introduced in. 1983 by Joddy Fodder They focused on general intelligence. Here, General Intelligence included attention control, flexibility and working memory, (Demetriou, 2018). However, theory of mind is a theory which still very appropriately describes the behavior of intellectually disabled people. Understanding point of views is difficult for patients with Intellectual Disability but this should not be confused with Empathy. People with Intellectual Disability are highly empathetically; they understand and express emotions very openly. However, this also depends upon who is receiving these emotions; they are more open with close family. Even crime offenders who were found to have Intellectual disability tested more on empathy and theory of mind than offenders who did not have Intellectual Disability. (Proctor & Beail, 2007)

As per our purpose we also were able to find new assessments for patients with Intellectual Disability, like Camber well assessment of Needs for Adults with Intellectual Disability, this scale is used to identify health which could include physical as well as mental health and social needs which includes presence or lack of social relationships and friendships.

Aberrant Behaviour Checklist was also included in the paper. This focuses upon multiple actors and emotions which included negative as well as positive emotions. Negative emotions included irritability, agitation, crying, and lethargy. Behaviour domains included social withdrawal, stereotypic behaviour, hyperactivity, noncompliance and inappropriate speech. Development Assessment was used for people with severe disabilities. This scale assesses 5 domains which include language, sensory motor skills, and activities of daily living like eating, showering,

cleaning and laundry etc, academics and emotional reception and expression too. To increase the adaptability and uses of this scale, we can also use it for People with Intellectual disability as they also suffer with language production and understanding, motor skills, they need assistance and support with Activities of daily living. For Emotions and mood, one can use Affect, Mood, Interest and Pleasure Questionnaire (MIPQ) which is a 25 Likert Scale based upon two subscales which are mood and pleasure can be used. Mood, Interest and Pleasure are important areas to be focused upon as it has been seen in researches that People with Intellectual Disability face mood disorders like depression. Mood fluctuations also influence our memory and other cognitive components, thus affecting overall performance.

This section examines the effectiveness of the identified interventions in improving various outcomes for parents of intellectually disabled children. These outcomes include parental stress, mental health, knowledge and understanding of intellectual disability, parenting skills, social support, and overall well-being. Recommendations and Future Directions Based on the findings of the reviewed publications, this section offers recommendations for practitioners, policymakers, and researchers. It highlights the importance of integrating evidence-based interventions into routine support services for parents of intellectually disabled children. Additionally, future research directions are suggested to further enhance our understanding of effective interventions and their long-term impact on parents and their children.

V. CONCLUSION

This systematic review provides an overview of recent approaches and interventions targeting parents of intellectually disabled children. The findings suggest that a variety of interventions have been developed to support parents in different aspects of their caregiving journey. However, the heterogeneity of interventions and methodological limitations of the included studies highlight the need for further research to evaluate the effectiveness and long-term outcomes of these interventions. Future efforts should focus on developing evidence-based interventions that address the unique needs of parents of intellectually disabled children and promote their well-being, coping strategies, and parenting skills. It was found that current research are focusing on biomedical etiologies and treatment options for Intellectual Disability. This review paper has focused on various assessments like Dash-II, Aberrant Behaviour Checklist, Camberwell Assessments and theories like that of Theory of mind and Casual Agency Theory. There is a shift between the assessments that were used earlier and the new assessments bring hope to explore areas of people with Intellectual Disabilities in terms of Behaviour and Emotion and not just Intellectual Quotient. Interventions targeting parents of

intellectually disabled children have the potential to significantly improve their well-being and enhance their ability to support their children effectively. This review highlights the diverse range of interventions available and their impact on parents' outcomes. By building on this knowledge, researchers and practitioners can develop and implement tailored interventions to meet the unique needs of parents and families.

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