

The Lifelong Journey with Intellectual Disability: Research Insights and Future Directions

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ABSTRACT

This literature review abstract explores the multifaceted experiences of individuals with Intellectual Disabilities (ID) across different age groups—children, adolescents, and adults—and the unique challenges faced by their parents during the COVID-19 pandemic. The review synthesizes existing research to shed light on the diverse ways in which the pandemic has affected the lives of people with ID and their families. Studies indicate that individuals with ID are at higher risk of contracting COVID-19 due to underlying health conditions and difficulties in adhering to safety protocols. Moreover, disruptions in support services and education have posed significant challenges for individuals with ID, leading to increased social isolation and limited access to necessary resources. The review also highlights the impact of the pandemic on the mental health of parents caring for individuals with ID, including increased stress, anxiety, and feelings of isolation. Additionally, financial strain and difficulties in accessing healthcare services have further exacerbated the challenges faced by these families. Overall, this review emphasizes the importance of understanding the unique experiences of individuals with ID and their families during the COVID-19 pandemic to inform the development of tailored support and interventions.

Keywords: *Multifaceted experiences, Intellectual disability (ID), Covid –19, Interventions, Social isolation, Parent-child relationship*

Intellectual disability, previously known as mental retardation all development is a neurodevelopmental disorder. Mild to profound intellectual disability can be present. The limitations must begin during the development period. Intellectual disability occurs

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in about one percent of the population. When a person's IQ score in a test is approximately 2 standard deviations below the mean on the normal curve, a person is considered to be intellectually disabled. The person's adaptive behaviour i.e. daily life skills are severely below a level appropriate for a person's age.

During the COVID-19 pandemic, caregivers and individuals with intellectual disabilities faced amplified mental health challenges and reduced social support, compounded by heightened demand for professional assistance and diminished informal aid. Isolation stemming from the pandemic contributed to inner distress and isolation among participants, affecting their mental health and disrupting their daily routines. Online support services, such as telehealth and personalized assistance, were deemed essential but underscored the necessity for enhanced accessibility to adequately address the hardships encountered by this population during the pandemic.

Observations in adults with intellectual disabilities reveal a range of internal and external resilience factors, though continued societal exclusion may impede their access to these resources over time. Health inequalities, such as high rates of overweight/obesity and relatively low hypertension prevalence, underscore the importance of early intervention and tailored health guidance, particularly among women navigating menopause. Efforts to adapt survey instruments for autistic adults and individuals with intellectual disabilities aim to enhance research accessibility and inform strategies for improving health outcomes and fostering inclusivity in adulthood. Despite facing challenges like stigma and dependency, competitive employment emerges as a pathway for societal integration and fulfilment among adults, while targeted interventions, inclusive healthcare models, and community-based support are crucial for promoting independence and well-being in the aging population with intellectual disabilities.

Research articles on children and teenagers with Intellectual disabilities were analyzed in this study. Two experimental research shed light on children's overall behavior getting affected due to physical exercises and listening to music. A 14-week physical program was administered to teenagers with ID and improvement were seen in the motor skills, Upper limb coordination, strength and resistance skills, and overall positive impact on quality of life on the Experimental group. Another experiment done to understand the effect of music therapy on children with ID showed that music therapy has enhanced effects towards individuals' empathy levels and emotional recognition.

METHODOLOGY

A comprehensive literature search was conducted across prominent electronic research databases such as Google Scholar and ScienceDirect, among others. Articles published between 2019 and 2024 were identified using keywords related to participant age categories (children, elderly), as well as various intervention strategies (sleep, caregiving, cognition, family, health, therapy). Duplicate studies were excluded by cross-referencing titles, authors, and publication dates. Only studies involving participants aged 8 to 65 years or older, encompassing diverse demographics including gender, nationality, race, and health status, were retained. Age categories were delineated following common classifications: 8-12 years as children, 13-18 years as adolescents, and 18-65 years as adults.

Systematic reviews and studies focusing on mobile health applications for elderly well-being were omitted from further analysis. Relevant studies were categorized and grouped based on thematic similarities. Each paper was thoroughly reviewed to extract pertinent information,

identify research gaps, and suggest future directions. Data extraction was carried out independently by two reviewers using a standardized template, encompassing study design, participant characteristics, interventions, outcomes, and key findings. Ethical procedures were followed throughout the review process. Out of 30 initially identified records, 26 were included in the final review.

REVIEW OF LITERATURE

Experiences of People with ID During Covid-19:

The series of articles collectively explore the nuanced impact of the COVID-19 pandemic on individuals with intellectual and developmental disabilities (IDDs), shedding light on the challenges faced by this vulnerable population, their families, and caregivers. The research identifies common themes, including disruptions in healthcare and education, the growing role of telehealth, and unique experiences of individuals with mild intellectual disabilities. A key finding is the substantial loss of in-person services, with many parents reporting reduced access to educational and healthcare resources for children with IDDs. Telehealth, particularly in the realms of education and medicine, emerged as a valuable resource during these disruptions, highlighting its potential as a sustainable delivery method beyond the pandemic (Jeste et al., 2020). Another article underscores the heightened vulnerability of individuals with intellectual disabilities during the COVID-19 pandemic, emphasizing the importance of comprehensive measures, including advance care planning, research, technological solutions, and legal adaptations, to ensure their protection, mental health, and well-being in current and future outbreaks (Courtenay & Perera, 2020). The experiences of individuals with mild intellectual disabilities, as detailed in a qualitative study from the Netherlands, reveal poignant themes of loneliness, challenges in adapting to preventive measures, and the critical role of social inclusion. The study underscores the need for tailored support, accessible information, and ongoing research to address the unique needs of this demographic during times of crisis (P. J. C. M. Embregts et al., 2022). Another facet of the pandemic's impact is explored through the lens of caregivers, emphasizing their increased mental health needs and decreased social support. The studies stress the urgency of policy interventions to address the mental health challenges faced by caregivers, especially those caring for individuals with intellectual disabilities (Willner et al., 2020). The research calls for sustained support for family caregivers facing pandemic challenges. It highlights significant losses in work hours, daytime activities, and social connections for individuals with intellectual disabilities, emphasizing the importance of meaningful work and urging awareness and support from authorities, employers, and the public. (Voermans et al., 2023). The study explores online support services for independent living, emphasizing their adaptability during the pandemic's initial weeks. It suggests integrating online support as a standard component for flexibility and responsiveness to diverse support needs. (Zaagsma et al., 2020).

Common research gaps across these articles include the lack of demographic factors in surveys, absence of specific phenotypic and genetic data, reliance on early cross-sectional snapshots, a consistent need for validated clinical measures, the necessity for prospective data collection to address gaps in infection rates and long-term impacts, limitations in sample size and representation urging broader research, gaps in understanding the mental health of caregivers and the effectiveness of support systems, a critical need to explore the relationship between the loss of work activities and mental health for individuals with intellectual disabilities, and the preliminary nature and limited time frame of studies on the long-term impact of online support. These gaps collectively stress the importance of more robust methodologies, diverse considerations, and comprehensive, longitudinal studies to

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understand the nuanced experiences of individuals with intellectual disabilities and their caregivers during and post the COVID-19 pandemic.

The future directions highlighted across these articles collectively underscore the need for enhanced telehealth delivery and quality, with a focus on improving access for under-resourced and diverse communities. There's an emphasis on educating providers and enhancing programs supporting in-home aides to better serve individuals with intellectual and developmental disabilities (IDDs). Moreover, the importance of longitudinal research to monitor the impact of COVID-19 on the health and well-being of individuals with IDD is emphasized, alongside a call for co-productive approaches involving families and caregivers. Accessible information, support for work-from-home arrangements, and longitudinal studies are recommended to understand the evolving impact of the pandemic on individuals with intellectual disabilities and their caregivers. Strategies to address the digital divide and extend support to individuals with complex needs are also highlighted. Additionally, there's a call for exploring post-pandemic employment opportunities and sustainable community participation initiatives to address the challenges faced by individuals with intellectual disabilities. In summary, the future directions emphasize the importance of comprehensive, inclusive, and longitudinal research to address the evolving needs and challenges faced by individuals with IDD and their caregivers in the wake of the COVID-19 pandemic.

Adults with ID (21 To 65 Years):

Several studies offer valuable insights into various aspects of intellectual disabilities (ID). One year-long intervention program involving 247 older adults, both with and without intellectual disabilities, demonstrated cognitive enhancement in both groups, with the intellectually disabled cohort exhibiting improved instrumental activities of daily living (Calatayud et al., 2024). Emphasizing the efficacy of multi-component approaches, the study underscored the importance of individualized care plans and social engagement for optimal outcomes in aging individuals with intellectual disabilities, while acknowledging limitations in assessment tools and sample size. Another study explored the family support networks of emerging adults with mild intellectual disability, revealing smaller family networks for this group and highlighting the need for tailored support to facilitate social integration and autonomy (Giesbers et al., 2020). Addressing the challenges of using existing survey instruments with autistic adults and individuals with intellectual disabilities, a separate study advocated for adaptations to ensure accessibility, inclusivity, and diverse perspectives in evaluations of interventions and services (Nicolaidis et al., 2020). Additionally, a study focused on overweight/obesity and chronic health conditions in individuals with intellectual disabilities, emphasizing the need for targeted health guidance, education, and longitudinal data collection (Ryan et al., 2021). Adding depth to the discussion, a study on resilience among individuals with intellectual disabilities highlighted sources such as acceptance, autonomy, social connections, and engagement in daily activities, emphasizing the vulnerability of this population and the importance of inclusive research approaches (Scheffers et al., 2023).

Another perspective from New South Wales, Australia, highlighted challenges faced by individuals with intellectual disabilities in genetic healthcare, stressing the need for co-designed resources, tailored education, and inclusive models of care for improved equity and appropriateness (Strnadová et al., 2023). Finally, an article discussed the importance of competitive employment for ID individuals, highlighting their aspiration for mainstream workforce inclusion and the pivotal role of supportive relationships and inclusive HR

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practices (Voermans et al., 2021). According to a study, grasping the frequency and inequalities in both mental and physical health issues among individuals with intellectual disabilities is essential for crafting successful interventions and enhancing their overall health results (Perera et al., 2020). The research study underscores the critical importance of fostering positive attitudes and mitigating stigmatization toward individuals with intellectual disabilities in the Arab world (Alnahdi et al., 2020). This can be achieved through initiatives aimed at enhancing knowledge and enhancing the quality of interactions. These studies collectively contribute to a nuanced understanding of intellectual disabilities, offering insights into interventions, social support, resilience, health concerns, and healthcare access for this diverse population.

It is identified that there are several research gaps across various areas related to individuals with intellectual disabilities. These gaps include limited exploration of self-reported family support experiences, the need for broader theoretical frameworks for understanding family dynamics, and the lack of studies from a social capital perspective. Additionally, there is insufficient inclusivity in previous studies on resilience among individuals with intellectual disabilities, a lack of research on their perspectives on genetic healthcare, and a need for more inclusive qualitative studies. Furthermore, there is a gap in understanding the correlation between overweight/obesity and chronic health conditions in older individuals with intellectual disabilities, as well as a need for adapted survey instruments for autistic adults and individuals with intellectual disabilities. These research gaps highlight the necessity for future studies to address the unique needs and experiences of individuals with intellectual disabilities across various domains.

The future directions outlined in the documents encompass several key areas for research and development. These include the need for more comprehensive and inclusive studies that actively involve individuals with intellectual disabilities, the adaptation and validation of survey instruments for autistic adults, the exploration of factors contributing to cognitive and functional development in older adults with intellectual disabilities, the assessment of resilience factors and the development of tailored interventions and policies, and the creation of accessible and inclusive models of genetic healthcare for individuals with intellectual disabilities. Additionally, future research should focus on understanding the sources of resilience, exploring factors associated with social capital, and developing targeted health services and interventions for individuals with intellectual disabilities.

Parents Experience and Their Relationship with Children Having ID:

Three studies collectively explore the multifaceted impact of childhood intellectual disability on parental well-being and family dynamics. The first study underscores the heightened emotional distress experienced by parents, particularly those with genetic causes, emphasizing the need for a comprehensive understanding of contributing factors. Genetic diagnoses are identified as significant influencers of caregiver distress. Limitations include the absence of data on parental physical health and a cross-sectional design (Baker et al., 2021). The second article delves into the challenges faced by mothers caring for children with intellectual disabilities during the COVID-19 pandemic, highlighting themes such as concerns about vulnerability to COVID-19 and the importance of tailored support and flexibility (P. Embregts et al., 2021). The third study focuses on parent-child relationship quality in families with intellectual disabilities, emphasizing the positive association between shared leisure activities and relationship quality. It suggests interventions should target shared parent-child time. Common themes across the articles include the need for

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diverse, longitudinal research, and tailored interventions to support families coping with intellectual disabilities (Zabidi et al., 2023).

The research gaps identified across the three articles revolve around the need for more comprehensive and diverse investigations into the impact of childhood intellectual disability and caregiving experiences. Key gaps include the call for future longitudinal studies that integrate genetic, developmental, and family factors to establish causal pathways and understand the evolving trajectories of parental distress. Additionally, there is a common emphasis on the importance of replication across diverse cultural and ethnic groups, consideration of disability severity, and the inclusion of fathers' perspectives. The limitations of small sample sizes, exclusive focus on mothers, and the cross-sectional nature of the data highlight the necessity for larger, more diverse participant groups and extensive, longitudinal studies to draw meaningful and generalized conclusions about the factors influencing parental well-being and the parent-child relationship quality in families with intellectual disabilities.

The three studies together highlight the imperative for future research to address the complexities of childhood intellectual disability, parental experiences, and family dynamics. Across the studies, there is a consistent call for conducting longitudinal research to elucidate the dynamic nature of these experiences over time. Key recommendations include exploring causal pathways integrating genetic, developmental, and family factors, investigating the impact of genetic diagnoses on parental mental health, and understanding trajectories of parental experience pre- and post-genetic diagnosis. The need for larger sample sizes, inclusion of diverse parental perspectives, and consideration of socioeconomic factors emerges as a common theme. Replication of findings across cultural and ethnic groups, assessment of intellectual disability severity, and exploration of the role of different leisure activities in parent-child relationships are also underscored. The articles collectively advocate for not only identifying challenges but also developing and evaluating tailored intervention strategies to support families and enhance overall well-being. In essence, the future directions emphasized in these studies emphasize a comprehensive, diverse, and longitudinal approach to advancing our understanding of the multifaceted impact of childhood intellectual disability on families.

Children with ID:

Four research articles which express the multidimensional impact of interventions and experiences on children with intellectual disabilities (ID) were analyzed. One study focused on a physical education program, bringing to light the positive effect of such program on motor skills and quality of life among children with ID (Özkan & Kale, 2023). Simultaneously, another study showcased the nature of music therapy, revealing how music significantly enhances empathy in adolescents with intellectual disabilities (Huang & Gu, 2024). We also focused on the prevalence and demographics, one study showed a detailed analysis of ID among 8-year-old children in the United States, emphasizing disparities across sex, race, and socioeconomic status (Patrick et al., 2021). Lastly, the fourth research article related to children with ID shed light on the healthcare landscape for children with intellectual disabilities, emphasized the need for their voices in patient experience data and addressing disparities in healthcare quality (Mimmo et al., 2020). These studies emphasize the importance of tailored interventions, ranging from physical education to music therapy, improving not only motor skills and emotional recognition but also overall quality of life. They highlight the broader societal picture, that there is a need for early identification and intervention to address disparities across demographic subgroups. Recognizing the diverse

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needs and potentials of this population is essential, not only for fostering individual development but also for promoting a more inclusive and equitable society.

Research gaps on the collective 4 articles analyzed indicate that there is a pressing need for comprehensive studies addressing critical aspects of individuals with intellectual disabilities (ID). Firstly, In the context of physical education activities on motor skills and quality of life, the research could've been more extensive with larger and diverse sample groups. Gaps were found in music therapy study, as it didn't incorporate emotional disorders, and lacked comparison of different music therapy types. In the context of ID prevalence, IT didn't include data on sub-populations. Lastly, concerning healthcare, there's a significant research gap in understanding causal links, development of valid patient experience measures, and the impact of poor care quality on healthcare inequity. Addressing these research gaps is crucial for advancing knowledge and improving the holistic well-being of individuals with intellectual disabilities.

Future directions in research for children with ID encompass a multidimensional approach. Firstly, physical education activities exploring specific types of physical activities with integration of technology could optimize such programs. Secondly, studies related to physical activity and music therapy should incorporate longitudinal studies as they will be significant to assess sustained impacts on motor skills, quality of life and in case of music therapy ascertain enduring emotional development effects. Comparative analyses of music therapy types and consideration of cultural influences contribute to refining therapeutic approaches. Within the context of ID prevalence, future research could include adaptive functioning scores, and explore intervention strategies. Lastly, in the healthcare sector, emphasis should be placed on developing pediatric-specific quality metrics collaboratively with children with ID, ensuring reliable identification and exploring indirect indicators of poor-quality care.

Adolescents with ID (16 to 21 Years):

The first article investigates the recognition of intellectual disability during hospital admissions in New South Wales, Australia, revealing a low recognition rate (23.79%) and advocating for targeted initiatives to improve recognition and reasonable adjustments (Walker et al., 2022). The second article focuses on using video modelling to teach social skills for employment to youth with intellectual disabilities, highlighting the effectiveness of this approach but acknowledging challenges in skill generalization (2020). The third article explores increased openness to external influences in adolescents with intellectual disabilities, emphasizing the vulnerability of these individuals to negative influences and the need for tailored interventions and support (Egger et al., 2021). The fourth article, conducted in Sweden, identifies a significantly increased overall mortality risk in young adults with mild intellectual disability, associating severity with higher mortality risk and emphasizing the need for targeted health interventions and support. Collectively, these articles underline the importance of recognizing intellectual disabilities, tailoring interventions, and addressing health disparities to enhance the well-being of individuals with intellectual disabilities across various contexts (Hirvikoski et al., 2021).

The study on predictors of mortality in individuals with intellectual disabilities (ID) identifies significant research gaps, emphasizing the necessity for national clinical guidelines to enhance healthcare for this population. Additionally, the study underscores limitations in recognizing ID, gaps in healthcare system responsiveness, and the lack of information on the social networks of individuals with ID. Specific causes of death in

varying ID severity levels, especially in mild ID compared to moderate to profound ID, remain unexplored. The scarcity of high-quality, population-based studies on mortality in individuals with ID is noted, indicating the need for more comprehensive research to tackle persistent health challenges. The study on adolescents with intellectual disabilities (ID) highlights crucial gaps in understanding their susceptibility to external influences. Longitudinal studies are recommended to uncover developmental trajectories in social judgment-making among adolescents with ID. The research underscores the need to explore underlying cognitive processes contributing to observed response patterns and advocates for more studies on interventions to help adolescents with ID make balanced social judgments and manage external influences effectively. These gaps underscore the necessity for ongoing research to address limitations and advance knowledge in the field of social judgment in adolescents with ID.

Future research in intellectual disabilities (ID) should prioritize the development of national clinical guidelines to enhance the health system. These guidelines ought to focus on increasing awareness among healthcare professionals and implementing scheduled health checks. Exploring recognition issues, especially for unidentified cases and misclassifications in moderate ID, is crucial. Additionally, research should investigate the impact of societal differences in welfare policies on health outcomes and the role of social networks in advocating for the rights of individuals with ID. In the context of teaching social skills for employment to youth with ID, future research should address study limitations by including both social and hard skills, examining skill maintenance, and conducting real work setting generalization probes. In social judgments of adolescents with ID, future research should explore underlying mechanisms, assess external validity, conduct longitudinal studies, and design tailored interventions to advance understanding in this domain. These research directions aim to refine strategies and support individuals with ID in real-world contexts, contributing to their overall well-being.

Key Findings

The key findings of the article encompass the multifaceted impact of the COVID-19 pandemic on individuals with intellectual and developmental disabilities (IDDs) and their families. The literature review synthesizes existing research to shed light on the diverse ways in which the pandemic has affected the lives of people with ID and their families. The studies indicate that individuals with ID are at higher risk of contracting COVID-19 due to underlying health conditions and difficulties in adhering to safety protocols. Disruptions in support services and education have led to increased social isolation and limited access to necessary resources for individuals with ID. The pandemic has also significantly impacted the mental health of parents caring for individuals with ID, resulting in increased stress, anxiety, and feelings of isolation, compounded by financial strain and difficulties in accessing healthcare services. The review underscores the importance of understanding the unique experiences of individuals with ID and their families during the pandemic to inform the development of tailored support and interventions. Additionally, the article highlights the need for enhanced telehealth delivery and quality, the importance of longitudinal research to monitor the impact of COVID-19 on the health and well-being of individuals with ID, and the necessity for comprehensive, inclusive, and longitudinal research to address the evolving needs and challenges faced by individuals with ID and their caregivers in the wake of the COVID-19 pandemic. By understanding and addressing these complex challenges, healthcare providers, policymakers, and communities can foster resilience and improve outcomes for this vulnerable population in the aftermath of the pandemic.

CONCLUSION

The comprehensive exploration of intellectual disabilities (ID) across various life stages and contexts reveals intricate challenges and potential interventions. In the context of the COVID-19 pandemic, the studies shed light on common issues faced by individuals with ID, such as disrupted healthcare and education access, emphasizing the crucial role of telehealth. Work experiences and online support services demonstrate adaptability and highlight the importance of meaningful activities. Research gaps include demographic factors, caregiver mental health, and comprehensive understanding of older individuals with ID. In the realm of adults with ID, positive impacts of interventions and resilience are evident, yet gaps in theoretical frameworks and health correlations persist. The studies on childhood ID stress the need for diverse, longitudinal research and inclusive healthcare practices. The collection emphasizes tailored interventions and the importance of replicating findings across diverse groups. Lastly, the exploration of ID during hospital admissions, video modelling for social skills, and mortality risk in young adults accentuates the need for targeted initiatives, comprehensive guidelines, and continued research. These insights collectively guide future endeavours to enhance support, inclusivity, and interventions for individuals with ID, fostering their well-being across various domains.

The conclusion of the article emphasizes the multifaceted impact of the COVID-19 pandemic on individuals with intellectual and developmental disabilities (IDDs) and their families. It highlights the challenges faced by this vulnerable population, including disruptions in access to crucial healthcare and educational services, the evolving role of telehealth, and the unique experiences of those with mild intellectual disabilities. The review underscores the need for tailored support, increased awareness, and long-term strategies to mitigate the impact on their well-being. Additionally, the article emphasizes the importance of comprehensive and inclusive approaches for individuals with intellectual disabilities, integrating physical education, music therapy, understanding demographic variations, and addressing healthcare inequities as crucial components of a holistic framework. The synthesis of research findings urges continued efforts in research, intervention, and societal support to promote a more inclusive and equitable society.

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Conflict of Interest

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