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A Comprehensive Review on Long-term Care Policies for Intellectual and Developmental Disabilities

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Abstract

Intellectual disability (ID) is a neurodevelopmental difficulty that affects both intellectual functioning and adaptive behaviour. The term IDD describes a broad range of long-term disorders that are caused by either physical or mental deficits. These disorders can influence numerous facets of life, such as self-care, social skills, communication, and education. This condition affects social and practical abilities daily. Conditions like cerebral palsy, Down syndrome, and autism spectrum disorder, Genetic predispositions, prenatal problems, traumatic births, and diseases in the early years can all lead to IDD. The foremost aim of this review is to provide awareness of Long-Term care policies that are available for IDD people. The review discovered the main obstacles and difficulties that people with IDD have while trying to get access to high-quality long-term care. It also examined the efficacy of current long-term care programs, compared strategies, and identified promising innovative models. The evaluation looked at past patterns, evaluated the success of ongoing initiatives, and pinpointed areas that need improvement. It also looked at current developments in care paradigms and technology. The review indicated that although LTC policies have improved, there are still issues and shortcomings that need to be addressed. It is stressed how crucial long-term planning and caregiver assistance are. People with IDD and their families may suffer as a result of inadequate LTC plans. The review emphasized how better policy is required.

Keywords: Intellectual developmental disabilities (IDD), innovative care models, caregiver assistance, Long Term Care (LTC), neurodevelopmental difficulty

INTRODUCTION

The hallmarks of intellectual and developmental disabilities (IDD) include notable deficits in cognitive capacities and adaptive behavior that start before the age of eighteen. These impairments affect a person's conceptual, social, and practical skills, influencing their daily activities. The WHO classification classifies IDD as a group of disorders that start during the developmental stage. IDD impacts an individual's cognitive abilities and adaptive behaviors, including a wide range of social and practical everyday skills (Schalock, R. L., Luckasson 2022) [1]. These disabilities involve limitations in reasoning, learning, problem-solving, and daily living skills like communication and self-care. IDD can have multiple causes, such as genetic factors and prenatal influences, and includes specific diagnoses like Down syndrome. It's vital to remember that not everyone with autism spectrum disorder (ASD) also has intellectual disability (IDD). Those with IDD may experience developmental delays, learning difficulties, communication challenges, and social interaction struggles, and are more susceptible to mental health

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issues. The experiences of each person with IDD are distinct, requiring personalized care based on their particular requirements and situation as shown in Figure 1.

Significance of Long-term Care Policies

Long-term care policies are vital for ensuring that individuals with intellectual and developmental disabilities (IDD) can live dignified and fulfilling lives. These policies address a wide range of needs, promoting well-being, independence, and social inclusion (Pinals et al., 2022) [2]. Comprehensive care includes not only physical assistance but also mental and emotional health support (Bisschops et al., 2022) [3]. Additionally, by fostering the development of independent living skills, they empower individuals with IDD to take control of their lives. Social inclusion is also a significant benefit of these policies (Mann et al., 2022) [4].

Long-term care policies offer respite care and other services that lessen caregiver stress (Nair et al., 2023) [5]. Financial assistance programs and funding mechanisms help manage healthcare costs, offering much-needed relief for families. Sustainable funding ensures the long-term availability of resources, preventing service shortages (Mpofu et al., 2020) [6].

These policies ensure fair treatment and safeguard individuals from harm (Cohen, 2020) [7]. By including advocacy and legal support provisions, they empower families and individuals with IDD to navigate complex systems and secure necessary services. Looking ahead, these policies are dynamic and can drive advancements in healthcare delivery by promoting research and the development of new, more effective therapies (Roos et al., 2022) [8]. Investing in workforce education and training is crucial for cultivating a skilled and qualified workforce capable of providing high-quality care. Policies that prioritize emergency preparedness ensure the continuity of care even during crises (Hanlon et al., 2018) [9].

Goals of the Study

A comprehensive review is necessary to identify gaps hindering optimal care delivery. It's essential to explore promising innovations such as advanced therapies and workforce development programs. By addressing these gaps and embracing new approaches, we can enhance the quality of care and support for people with IDD, ensuring they receive the comprehensive, effective services they need to thrive. Policymakers can benefit from insights on best practices and fostering community inclusion by evaluation, innovation, gap analysis, policy development and best practices.

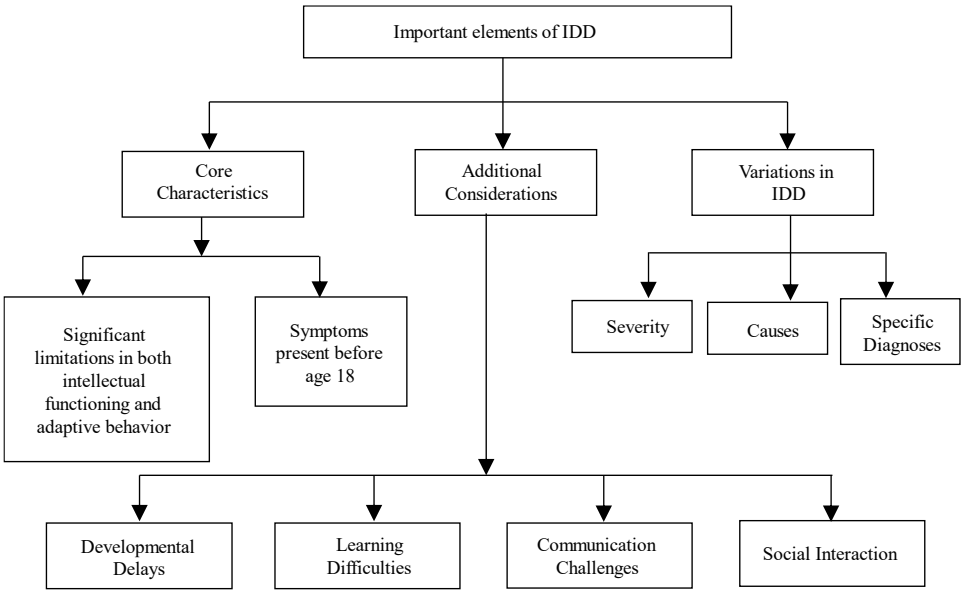

Figure 1. Elements of intellectual and developmental disabilities.

Scope of the Review

A thorough long-term care review for people with IDD requires a multi-pronged approach. We need to examine laws, funding, and resource allocation to assess how well they support care services. The effectiveness of different models like community programs and institutions needs evaluation, along with identifying best practices and improvement areas. Exploring technology, integrated care, and assistive devices to enhance healthcare delivery is crucial. Workforce development through training programs, while acknowledging challenges faced by professionals, is vital. Examining methods for measuring care impact, caregiver resources, and disparities in access across demographics and locations is essential. Finally, analyzing cultural competency of services to meet diverse needs is important. We may strive for a more all-encompassing, just, and efficient long-term care system for individuals with IDD by addressing these issues.

EVOLUTION OF THE POLICIES

The evolution of long-term policies for people with intellectual impairments has resulted in notable changes to legislative frameworks, service models, and societal attitudes. This progression demonstrates a more comprehension and dedication to human rights, inclusivity, and self-determination as shown in Table 1.

CURRENT STATUS OF LONG-TERM POLICIES

With an emphasis on inclusion, rights, and individualized support, long-term policies for people with intellectual impairments are evolving. Together, a number of laws and programs make the environment more welcoming to those with intellectual disabilities. Educational laws, such as Individualized Education Programs (IEPs) and the Individuals with Disabilities Education Act (IDEA), prioritize inclusive education with appropriate support services (Carrier, 2021) [10]. The Affordable Care Act (ACA) protects against healthcare discrimination and ensures access through programs like Medicaid and Medicare. Employment First initiatives emphasize integrated employment with training and support, while the Americans with Disabilities Act (ADA) safeguards against discrimination in workplaces and other settings (Vaitsiakhovich, N., & Landes, S. D. (2023); Friedman et al., 2023) [11, 12]. Supported decision-making is gaining traction as an alternative to guardianship (Whaley & Williamson, 2023) [13].

Policies prioritize community living with home and community-based services (HCBS) and financial assistance programs like Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Social programs like Special Olympics and public awareness campaigns further promote social inclusion and acceptance.

Table 1. Major milestones in history of intellectual and developmental disabilities, ranging from the early 1900s to 2010.

Period	Milestone	Description
Early 1900s	Institutional Care Centers	Creation of facilities that isolate and provide only rudimentary education to people with intellectual disability
1930s - 1940s	Eugenic Sterilization Laws	Implementation of laws promoting segregation and sterilization of people with intellectual disabilities
1960s - 1970s	Deinstitutionalization Movement	Closure of institutions and community integration for individuals with intellectual disabilities
1970s - 1980s	Legal Foundations	Education for All Handicapped Children Act (IDEA), Rehabilitation Act of 1973 (Section 504), and other policies
1990s	Americans with Disabilities Act (ADA)	Ensuring accessibility and rights for individuals with disabilities
2000s	UN Convention on the Rights of Persons with Disabilities (CRPD)	Global commitment to disability rights
2010	Affordable Care Act (ACA)	Healthcare provisions for individuals with disabilities

Advancements in technology, including communication devices and adaptive learning tools, are also being increasingly integrated into support plans (Zander et al., 2023) [14]. This comprehensive network of policies and initiatives works towards a future where people with intellectual disabilities can live fulfilling and empowered lives.

INNOVATIONS AND ADVANCEMENTS IN LONG-TERM CARE POLICIES

Person-centered care is essential, with personalized care plans based on each person's requirements, preferences, and objectives. Self-directed services empower individuals to manage their care, choosing service providers and personal care aides (Wiesel et al., 2024) [15]. Advancements in assistive technology, like wearable health monitors and communication devices boost independence and safety (Chakraborty et al., 2023) [16]. Telehealth expands access to care by offering remote consultations and therapy sessions. Investing in Home and Community-Based Service**s** (HCBS) allows individuals to live in their own homes or supported living arrangements like co-housing, fostering integration within communities (Che & Cheung, 2024) [17]. Customized employment creates job opportunities aligned with individual skills and interests, while some companies specifically hire and train people with intellectual disabilities. Finally, enhanced education practices involve specialized teacher training, technology integration for better learning and programs that prepare students for the transition to adulthood (Mitchell & Sutherland, 2020) [18]. This combined approach strives to empower individuals with intellectual disabilities and foster their independence and inclusion.

LONG-TERM CARE POLICIES: SHORTCOMINGS AND DIFFICULTIES

Global long-term care (LTC) policies face many obstacles that prevent the provision of comprehensive and fair care for the aged and disabled. Since many long-term care (LTC) policies do not sufficiently cover basic services like specialized therapies and personal support with everyday activities, accessibility and affordability are the main areas of concern (Prince et al., 2015 & Doty et al., 2020) [19]. Due to the significant coverage gaps that arise from this, people and families must pay hefty out-of-pocket expenses, particularly if they do not have enough long-term care insurance. These problems are made worse by a persistent scarcity of trained caregivers in-home care and assisted living facilities, which results in subpar care and insufficient staffing. Care continuity is further disrupted, and the overall quality of care is reduced by high caregiver turnover rates, which are linked to poor wages and difficult work environments. Fragmentation also affects coordination and integration of care services, resulting in gaps and inefficiencies in the provision of services between healthcare providers and long-term care institutions. Without enough assistance, informal caregivers—who are mostly family members—face heavy responsibilities, such as restricted access to training programs and respite care. To guarantee that LTC services are available, inexpensive, and of the highest calibre for everyone who needs them, there is an immediate need for comprehensive reform. This need is highlighted by the gaps in funding and legislation as well as the complicated qualifying requirements for public LTC programs.

Discussion of Barriers to Effective Policy Implementation

Long-term care (LTC) systems grapple with several challenges. Financial limitations restrict resources for facility development, staff training, and essential supplies, impacting service quality. The high cost of care often outpaces available funding, creating service gaps and unequal care (Wysocki et al. 2015) [20]. A complex regulatory environment with numerous and evolving regulations burdens LTC facilities with compliance difficulties. Low pay, hard working conditions, and little prospects for professional progression all contribute to excessive staff turnover, which lowers morale and compromises continuity of service. Fragmented service delivery due to poor coordination between healthcare providers, social services, and LTC institutions results in communication breakdowns, inefficient service provision, and fragmented care. Insufficient preparation and assistance during shifts in healthcare environments result in medical mistakes, patient discontent, and elevated healthcare expenses. Public awareness remains a significant issue, with limited knowledge about long-term care (LTC) options, insurance, and services hindering informed decision-making and access to appropriate

care. The lack of educational resources on LTC planning, rights, and accessible supports further contributes to disparities in service utilization. Additionally, political and stakeholder misalignment creates roadblocks for legislative reform and hampers efforts to improve care standards. Resistance to change from vested interests, such as insurers and healthcare providers can further impede progress toward a more robust LTC system as shown in Figure 2.

Impact of Inadequate Policies on Individuals with IDD

Inadequate policies have a wide-ranging and profound effect on people with intellectual and developmental disabilities (IDD) and their families, impacting many facets of their lives. Prolonged waitlists for vital support like specialized therapies and residential placements are caused by limited access to important services due to insufficient policies. Inconsistent are standards brought on by a lack of enforcement of policies may subject people with IDD to inadequate care circumstances. Similar restrictions apply to educational and career chances, since insufficient governmental support restricts access to inclusive education and career training, impeding social integration and job opportunities. These difficulties worsen caregiver fatigue and stress, which is further compounded by a dearth of support services and respite care.

IMPACT OF CAREGIVERS IN LTC FOR INDIVIDUALS WITH IDD

To provide long-term care (LTC) for people with intellectual and developmental disabilities (IDD), caregivers are essential in various aspects of the patient's life. Their multifarious contributions encompass direct care (Embregts et al., 2021) [21], emotional support (Robinson et al., 2020) [22], advocacy, service coordination (Dixon et al., 2020) [23], future security and long-term planning (Cuskelly et al., 2024) [24]. Caregivers provide:

- Daily life support and direct care
- Mental and Emotional Assistance
- Protection of Rights and Advocacy
- Management and Coordination of Services Fostering Independence and Developing Skills
- Engagement of the Family and the Community
- Future Security and Long-Term Planning

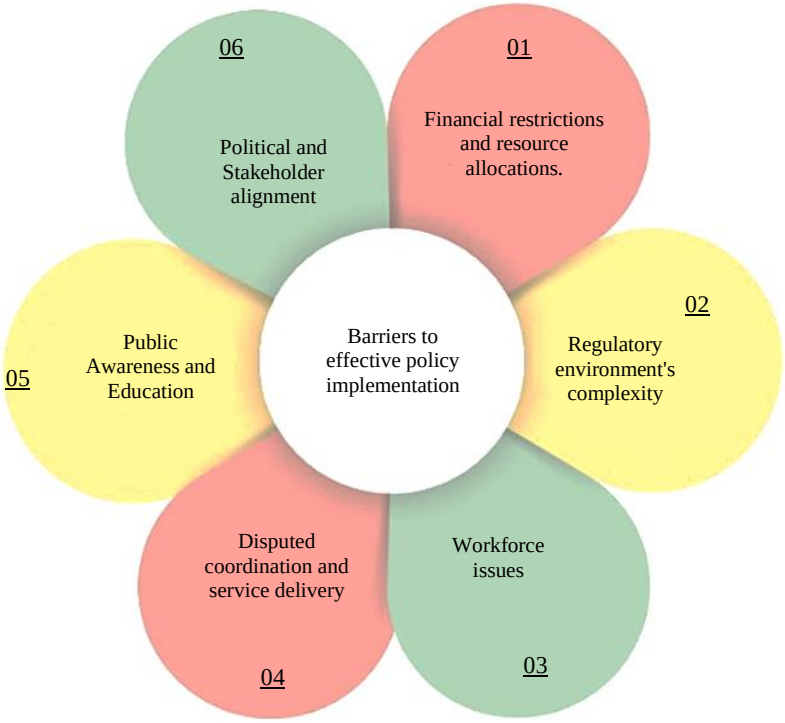

Figure 2. Barrier to effective policy implementation.

CONCLUSION

This review examines the current landscape of long-term care policies for individuals with intellectual and developmental disabilities (IDD), identifying areas for improvement while acknowledging significant advancements. It explores various aspects of care, including healthcare, employment, housing, legal rights, education, and the crucial role of caregivers.

Positive developments in long-term care policy for people with IDD include a shift towards integrated healthcare models that better address their specific needs. Inclusive education practices are gaining traction, promoting opportunities for learning alongside peers. Employment assistance programs are empowering individuals with IDD to participate in the workforce.

However, the review also identifies persistent challenges. Disparities in access to healthcare remain a concern, with some individuals facing difficulties obtaining necessary services. There is a lack of adequate transition programs to support individuals with IDD as they move through different life stages. Furthermore, the availability of affordable housing options specifically designed to meet their needs is insufficient.

To bridge these gaps, the review emphasizes the need for increased funding for long-term care services and a strong commitment to improving care. Developing more inclusive and comprehensive policies that address the diverse needs of people with IDD is essential. The review also recognizes the pivotal role caregivers play in ensuring a sustainable and efficient care system. Their contributions deserve acknowledgment and support. By valuing their efforts and providing the necessary resources, we can create a more robust long-term care system for people with IDD.

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