Advancing Care for Individuals with Intellectual and Developmental Disabilities (IDD): A Review of Global Guidelines and Practices, Gap Analysis, and Recommendations for Improvement

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Abstract

Objective: To conduct research, identify gaps in current care, and highlight key opportunities for improving primary care for individuals with Intellectual and Developmental Disabilities (IDD), ensuring that care is tailored to meet the unique needs of this population.

Methods: A literature review was conducted to examine and analyze existing global clinical guidelines for the primary care of individuals with IDD. In addition, monthly global consultative meetings were organized to promote collaboration among healthcare professionals and experts specializing in IDD and related areas of care. These collaborative sessions focused on synthesizing recent empirical research, expert insights, and firsthand knowledge. To facilitate the identification of actionable opportunities for improvement, a system based on the 2018 Canadian Consensus Guidelines for the Primary Care of Adults with Intellectual and Developmental Disabilities[i] was adopted.

Insights: The gaps in global clinical guidelines and resources for IDD highlight significant challenges and opportunities for improvement. These include a lack of tailored frameworks and tools, resulting in fragmented and inconsistent care across regions. The absence of centralized platforms for accessible guidelines leaves caregivers and providers struggling to find up-to-date practices. Pervasive stigma, low awareness, and cultural insensitivity contribute to delayed diagnoses and social isolation, especially in low-income regions. Additionally, the lack of intersectionality in guidelines, limited involvement of individuals with IDD and their families in policymaking, and insufficient engagement of other interested parties such as local non-profit organizations, advocacy groups, and community leaders, exacerbate disparities both in urban and rural areas. Insufficient training and support for caregivers further hinder quality care. Addressing these gaps through inclusive, culturally sensitive models and tailored policy innovations designed to align with the unique social, economic, and cultural contexts of each country can significantly improve care for individuals with IDD worldwide.

Conclusion: This paper emphasizes the need for more adaptable care models to address the diverse and complex needs of individuals with IDD. It underscores the importance of policy interventions to address systemic challenges, such as increasing awareness, reducing stigma, ensuring specialized training for healthcare professionals, and improving access to resources and support services for individuals with IDD. By advocating comprehensive clinical guidelines and tailored policy reforms, this paper aims to improve care and support for individuals with IDD globally, ensuring they receive the necessary resources to thrive.

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- Outlines key opportunities to improve care for individuals with IDD by promoting accessible, culturally sensitive, and effective support systems that address the diverse needs of the global IDD community.

- Identifies the most urgent gaps within global clinical guidelines for IDD, including the lack of comprehensive frameworks, absence of centralized care platforms, infrequent updates to resources, low levels of awareness, insufficient culturally relevant and intersectional frameworks, and inadequate specialized training and support for caregivers.

- A discussion on developing adaptable care models, addressing systemic barriers, and advocating for comprehensive guidelines and policy interventions to enhance global IDD care.

INTRODUCTION

Target Audience

This paper is primarily intended for mental health and social care professionals and trainees, including but not limited to primary care providers and other healthcare practitioners, as well as professionals serving individuals with Intellectual and Developmental Disabilities (IDD) in primary care and related public or social health contexts.

PURPOSE

Objective and Scope

This paper examines the current state of care for individuals with IDD, analyzing global clinical guidelines and related resources to identify key gaps and areas for improvement. It highlights the various challenges faced by individuals with IDD and emphasizes the need for more inclusive, person-centered care models that can be adapted to different cultural and socioeconomic contexts. The paper also emphasizes the importance of policy interventions to tackle systemic barriers and promote comprehensive approaches to IDD care. The aim is to encourage a global shift toward more effective support systems for individuals with IDD, ensuring their unique needs are met in both healthcare and social service settings.

This approach closely aligns with the core principles of the World Health Organization's Primary Health Care (PHC) framework[ii], which asserts that every individual, everywhere, has the right to achieve the highest attainable level of health. PHC is designed to address a person's healthcare needs across the entire continuum, including health promotion, disease prevention, treatment, rehabilitation, and palliative care. Crucially, PHC ensures that care is personalized, centered on the individual's unique needs, and respects their preferences. Recognized as the most inclusive, equitable, and cost-effective model for achieving universal health coverage, PHC also plays a vital role in strengthening health systems' resilience, enabling them to effectively prepare for, respond to, and recover from health crises. Implementing the Primary Health Care Approach: A Primer[iii], published in March 2024, serves as a crucial tool for policymakers to advocate for investment in primary care, drive practical changes, and advance progress towards universal health coverage and good health for all.

DEFINITIONS

Caregiver: A caregiver is a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury, or disability. The term "family caregiver" describes individuals who care for members of their family of origin but also refers to those who care for their family of choice. This could be members of their congregation, neighbors, or close friends. Family caregivers play a significant role in health care, as they are often the main source of valuable information about the patient.[iv]

Community-Based Health Care: Includes services delivered by a broadly defined community health workforce, according to their training and capacity, encompassing a range of health workers, lay and professional, formal and informal, paid and unpaid, as well as facility-based personnel who support and supervise them and provide outreach services and campaigns. Where applicable, specific occupational groups and their roles are highlighted. In every community, there are local actors, relationships, and processes that intersect with the health sector and are central to delivering high-quality, people-centered health care and to building health system resilience. Relevant actors include local authorities, faith leaders, non-governmental organizations (NGOs), and community groups, such as women's, scouting, and youth groups. As trusted members of the community, the community health workforce usually has strong ties with these groups.[v]

Equity Seeking:[vi] Refers to communities and groups that experience significant collective barriers in participating in society. This could include attitudinal, historical, social, and environmental barriers based on age, ethnicity, disability, economic status, Indigeneity, gender identity and gender expression, nationality, race, sexual orientation, and more.

Evidence-Based Practice (EBP):[vii] It is a process used to review, analyze, and translate the latest scientific evidence. The goal is to quickly incorporate the best available research, along with clinical experience and patient preference, into clinical practice, so informed patient-care decisions can be made.

Integrated services:[viii] These are health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation, and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector and according to their needs, throughout the life course.

Intersectionality:[ix] It is an approach or lens that recognizes that health is shaped by a multi-dimensional overlapping of factors such as race, class, income, education, age, ability, sexual orientation, immigration status, ethnicity, indigeneity, and geography.

Intellectual and Developmental Disability (IDD): IDD refers to various lifelong limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years. These limitations differ in severity and type among people with IDD and can vary during a person's lifespan. IDD encompasses intellectual disability, developmental disability, learning disability, and autism spectrum disorder.[x]

Despite facing these challenges, individuals with IDD possess unique strengths and lead fulfilling lives when provided with the right support. However, people with IDD experience disproportionately high rates of poor health outcomes and long-term co-occurring conditions, including diabetes, mental health issues, maternal mortality, addiction, violence, and preventable deaths. These disparities are often exacerbated by limited access to appropriate trauma-informed healthcare and services, as well as a lack of training for healthcare professionals on IDD, which contributes to widespread misunderstandings about these disabilities.[xi]

Mental Health:[xii] Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships, and shape the world we live in. Mental health is a basic human right. And it is crucial to personal, community, and socio-economic development.

Patient-centered care:[xiii] It focuses on the patient and the individual's particular healthcare needs. The goal of patient-centered health care is to empower patients to become active participants in their care. This requires that healthcare providers develop good communication skills and address patient needs effectively. Patient-centered care also requires that the health care provider become a patient advocate and strive to provide care that not only is effective, but also safe.

People-centered care:[xiv] It is an approach to care that consciously adopts the perspectives of individuals, carers, families, and communities as participants in and beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways. People-centered care also requires that people have the education and support they need to make decisions and participate in their care.

Primary Care:[xv] It is a model of care that emphasizes first contact, accessible, continuous, comprehensive, and coordinated person-focused care. It aims to optimize population health and reduce disparities by ensuring that all subgroups have equal access to services. The five core functions of primary care include: first-contact accessibility, which provides a strategic entry point and improves access to health services; continuity, which fosters long-term personal relationships between individuals and their healthcare providers or teams; comprehensiveness, ensuring a broad range of services such as promotive, preventive, curative, rehabilitative, and palliative care; coordination, which organizes services across different levels of the health system and over time; and people-centered care, which equips individuals with the education and support needed to make informed decisions and actively participate in their care.

Primary Health Care (PHC): It is a whole-of-society approach to health that aims to maximize the level and equitable distribution of health and well-being by focusing on people's needs and preferences as early as possible along the continuum, from health promotion and disease prevention to treatment, rehabilitation, and palliative care. The PHC approach accelerates progress towards achieving Universal Health Coverage (UHC) and health security. At the same time, it enables health systems to have all essential health services readily available, of high quality, accessible and affordable to communities, as close as possible to people's everyday environment. PHC combines multisectoral policy and action, community engagement, and high-quality services. It integrates population and individual-level health interventions, and shifts efforts from a reactive biomedical approach to illness to a more holistic and proactive approach to health and well-being.[xvi]

Trauma-informed care (TIC):[xvii] TIC takes a trauma-informed approach to the delivery of behavioral health services that includes an understanding of trauma and an awareness of the impact it can have across settings, services, and populations. TIC views trauma through an ecological and cultural lens and recognizes that context plays a significant role in how individuals perceive and process traumatic events, whether acute or chronic. TIC involves vigilance in anticipating and avoiding institutional processes and individual practices that are likely to retraumatize individuals who already have histories of trauma. TIC upholds the importance of consumer participation in the development, delivery, and evaluation of services.

METHODOLOGY

This paper follows a structured approach to assess and analyze common health needs, clinical guidelines, and workforce competencies in the healthcare sector concerning individuals with Intellectual and Developmental Disabilities (IDD). Our process began with an extensive review of globally published guidelines, drawing on resources such as World Health Organization (WHO) documents, peer-reviewed articles, case studies, and materials from government health agencies, and other reputable health organizations. The guidelines were identified through a systematic online search strategy, utilizing databases such as PubMed, Google Scholar, JSTOR, PsycInfo, and the official websites of international health organizations. The objective was to identify relevant standards and best practices in the care of individuals with IDD.

To compare existing guidelines with workforce competencies, we employed qualitative methods, specifically thematic analysis. We organized monthly global consultative meetings to foster collaboration among healthcare professionals and experts in IDD and related care fields. During these sessions, we synthesized recent empirical research, expert insights, and firsthand knowledge. This collaborative approach allowed us to identify key themes, explore regional differences in how healthcare providers interpret and implement the guidelines, and identify both the strengths and gaps in current healthcare practices for individuals with IDD.

Subsequently, we conducted a gap analysis to uncover discrepancies between current standards outlined in clinical guidelines and the realities reflected in healthcare practices and publications globally. This analysis aimed to identify areas for improvement to align healthcare systems more closely with global benchmarks, such as those set by the WHO. We then proposed actionable opportunities for improvement, emphasizing the importance of adapting these to suit diverse regional contexts and conditions.

Finally, we discuss strategies for adopting these improvements, addressing potential challenges that may emerge. This includes practical solutions designed to support healthcare organizations and policymakers in seamlessly integrating these areas for improvement into their practices for more comprehensive care for individuals with IDD.

LITERATURE REVIEW

A comprehensive literature review of existing global clinical guidelines for the care of individuals with IDD was conducted to evaluate the current state of care and identify opportunities for improvement through gap analysis. This review was carried out in collaboration with healthcare professionals, experts in IDD, and specialists in related fields, ensuring a diverse and well-rounded perspective. The primary objective was to integrate recent research findings, expert insights, and practical knowledge from those working directly with individuals with IDD.

The following section provides a summary of the key global clinical guidelines for the care of individuals with IDD. These guidelines, developed by various health organizations and experts, outline the best practices, diagnostic criteria, intervention strategies, and approaches to long-term care, offering valuable insights into the provision of effective and comprehensive support.

Overview of Existing Global Clinical Guidelines for Individuals with Intellectual and Developmental Disabilities (IDD)

The 2018 Canadian Consensus Guidelines for Primary Care of Adults with Intellectual And Developmental Disabilities (IDD)[xviii] set important standards to guide clinical decision-making. Developed by a team of family physicians, nurses, psychiatrists, and other experts with extensive experience in caring for people with IDD, these guidelines provide practical advice and point to valuable clinical tools for primary care providers. They advocate for a holistic, person-centered approach to healthcare, emphasizing the integration of diverse knowledge sources, including empirical research and patient experiences. Effective communication is paramount, ensuring that patients and caregivers are actively involved in decision-making, while honoring individual preferences and values. The guidelines call for tailored health assessments to detect and prevent disease and the development of personalized Health Action Plans. They also stress the importance of family involvement, vigilant monitoring for abuse, and comprehensive planning for life transitions. Physical health recommendations encompass regular screenings for various conditions and individualized care plans to address specific health needs. Mental health is equally critical, with strategies to foster social networks and interpret challenging behaviors as indicators of underlying distress. Recommended interventions include counseling and trauma-informed approaches, alongside careful management of medications. Additionally, the guidelines emphasize the necessity of early detection and customized care plans to facilitate timely interventions as these individuals age.

Toolkit for Primary Care Providers: Health Care for Adults with Intellectual and Developmental Disabilities[xix] are extensive resources designed to support healthcare providers in delivering comprehensive and effective care to this population. Originally introduced in 2011 by the Developmental Disabilities Primary Care Initiative in collaboration with Medication Use Management Services (MUMS), these tools were updated in 2019 with valuable input from family physicians, primary care providers, and caregivers who have experience in caring for individuals with IDD. The toolkit aligns with the abovementioned Canadian Consensus Guidelines on the Primary Care of Adults with IDD and aims to address critical areas of preventive care that may often be overlooked, such as routine health screenings, immunizations, and medication reviews. The tools are categorized into various functional types to support providers in different aspects of care delivery. Tip sheets offer practical advice on adapting healthcare practices to suit the unique needs of adults with IDD, enabling better communication and personalized care. Point-of-care forms serve as quick-reference guides for making informed healthcare decisions, conducting health checks, and performing mental health assessments. Monitoring charts help track health issues over time, forming a structured approach to evaluating and improving interventions. Additionally, patient and caregiver tools are included to enhance healthcare interactions, ensuring that patients and their families are actively engaged in the care process.

The Centre for Addiction and Mental Health (CAMH) provides Intellectual & Developmental Disabilities (IDD): The Role of the Primary Care Practitioner,[xx] a guide for healthcare professionals supporting individuals with IDD, including autism spectrum disorder (ASD) and related conditions. This resource emphasizes the importance of personalized care that respects each person's unique needs and preferences. Practitioners are encouraged to engage patients in conversations about how they wish their condition to be discussed, using either person-first or identity-first language to foster respect and understanding. CAMH underscores the challenges individuals with IDD often face in expressing their symptoms, making the involvement of families and caregivers crucial in uncovering concerns. Screening tools, combined with caregiver insights, can help identify potential mental health issues. Misdiagnosis is a significant risk when psychiatric symptoms are mistakenly attributed to IDD, and practitioners are urged to assess changes in the individual's usual behavior to identify underlying conditions. The guide highlights the need for caution in medication use, as people with IDD may be more sensitive to side effects.

Additionally, non-pharmacological treatments such as cognitive-behavioral therapy,[xxi] mindfulness practices, and innovative approaches like virtual reality therapy can be highly effective when tailored to the individual's needs. Emergency care planning is another vital focus, helping patients and caregivers manage crises through well-structured plans developed collaboratively. CAMH also stresses the importance of supporting family caregivers, recognizing the challenges they face, and encouraging practitioners to connect them with resources, plan for future needs, and offer strategies to reduce stress and improve overall well-being.

The American Association on Intellectual and Developmental Disabilities (AAIDD)[xxii] offers a comprehensive range of resources and tools aimed at enhancing support for individuals with IDD. Central to their offerings is the Supports Intensity Scale (SIS), which includes two versions: the Adult Version (SIS-A) for individuals aged 16 and older and the Children's Version

(SIS-C) for those aged 5 to 16. These assessment tools evaluate the support needs across essential life domains, emphasizing the necessary support for fostering independence rather than merely identifying individual deficiencies. AAIDD also provides the Guidelines for Interviewing People with Disabilities[xxiii] and Guidelines to Professional Conduct,[xxiv] which serve as an ethical framework for professionals in the field. These guidelines emphasize the importance of respect, integrity, and accountability, encouraging effective communication and safeguarding the dignity and confidentiality of individuals with IDD.

In addition, AAIDD offers a variety of publications and training manuals[xxv] designed to strengthen the skills of professionals working with individuals with IDD. These resources cover important topics such as trauma-informed care, cooking skills for independence, person-centered planning, and positive behavior support training. Collectively, these materials aim to enhance the quality of life for individuals with IDD while being accessible at a cost.

The National Center for START Services at the University of New Hampshire Institute on Disability's, Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities,[xxvi] also known as IDD-MH Prescriber Guidelines, offer a vital framework for healthcare professionals managing the mental health care of individuals with IDD. These guidelines emphasize the importance of mental health, psychiatric assessments, cultural competency, and sensory considerations to address the unique needs of this population effectively. A key focus is on communication and cultural competency, which ensures that healthcare providers engage sensitively with patients and their families. The guidelines also provide direction on psychiatric and medical assessment considerations, advocating for trauma-informed care to navigate the complexities of evaluating mental health in individuals with IDD. In addition, the guidelines present best practices in diagnosis and treatment, offering insights into managing various mental health disorders, including anxiety and schizophrenia, while stressing the significance of psychopharmacology and developmental factors in treatment planning. They further explore the impact of trauma, stress, grief, and loss, equipping providers with strategies to support patients through these challenging experiences. Lastly, the guidelines underscore the importance of incorporating lived experience and patient perspectives, fostering a holistic and person-centered approach to mental health care for individuals with IDD.

The Autism and/or Intellectual Disability Knowledge Exchange Network (AIDE Canada), Caring for the Caregivers of Individuals with Intellectual and/or Developmental Disabilities: Toolkit[xxvii] is designed to address the unique challenges faced by family caregivers of individuals with autism and intellectual and/or developmental disabilities. These challenges can significantly impact the mental and physical health of caregivers. The toolkit aims to enhance understanding of caregiver experiences, emphasize the importance of support, and provide practical information, tips, and resources. The toolkit is structured into several sections. It begins with a description of the various challenges caregivers may encounter, followed by an exploration of risk factors that can exacerbate these difficulties. Additionally, it outlines protective factors that can help families manage stress and cope with pressures. Further, the toolkit offers tips and resources for building a support network and enhancing protective factors for caregivers and their families. It also includes activities designed to help caregivers identify their needs and develop effective support networks. Overall, the toolkit serves as a valuable resource for improving the well-being of caregivers and their families.

The Arc's, Training Needs of Professionals who Serve People with I/DD and Mental Health Needs and their Families[xxviii] outlines essential training areas identified by focus group participants for professionals working with individuals with IDD and mental health needs. The guidelines emphasize five key content areas where professionals require training: philosophical understanding; practical skills; communication skills; team-building skills; and knowledge of available resources. Professionals are encouraged to recognize the inherent dignity of individuals with IDD and interpret their behaviors as communication rather than defiance. Training should focus on essential interventions such as crisis management and trauma-informed care, while also ensuring treatment plans are accessible and culturally sensitive. Effective communication and rapport-building with individuals and families are vital, as is fostering collaboration among family members, professionals, and community resources to ensure coordinated care. Additionally, professionals need to understand the landscape of available services and funding mechanisms to navigate complex support systems effectively. The guidelines advocate for diverse training formats, including webinars and in-person sessions, to engage a wide range of professionals and integrate training into ongoing professional development. Ultimately, these guidelines aim to enhance the skills and knowledge of professionals, enabling them to provide more effective and compassionate support to individuals with IDD, and their families.

A Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities (IDD),[xxix] developed in collaboration with the MARC grant, the Center for Disability Services, the HEARTS initiative, and the University at Albany's School of Social Welfare, is a comprehensive resource designed to help professionals better understand and address the trauma-related needs of individuals with IDD. The toolkit emphasizes the importance of self-care and resilience for support staff, acknowledging the impact of their own trauma experiences or the trauma they witness in their work. It highlights the significance of self-care in improving care quality, reducing restrictive interventions, and decreasing staff turnover. The toolkit also focuses on the higher prevalence of adverse childhood experiences and trauma in individuals with IDD, stressing the need for trauma-informed care in this population. It provides guidance on understanding behaviors in individuals with trauma histories, recognizing that these behaviors may not always have a clear purpose but could be anxiety-driven responses.

Additionally, it includes strategies for planning trauma-informed interventions and creating support plans that account for trauma-related needs. Lastly, the toolkit offers recommendations for agency administrators and staff to ensure trauma-sensitive care within organizations, including minimizing restrictive practices, conducting trauma-sensitive interviews, and training staff to better address the complex needs of individuals with IDD who have experienced trauma. It serves as a comprehensive guide for enhancing the quality of care for this vulnerable group by incorporating trauma-informed principles throughout professional practice.

The World Health Organization (WHO), in collaboration with international partners, has developed a comprehensive five-part package on Caregiver Skills Training (CST) for families of children aged 2–9 years with developmental delays or disabilities, including autism.[xxx] This initiative aims to equip caregivers with practical skills to enhance children's engagement in activities, communication, and positive behavior, as well as to support daily living skills.[xxxi]

The first component of the CST package is an introduction guide that outlines the course structure and content, highlighting how each element can be utilized to support caregivers. It serves as a foundational resource, detailing the requirements for delivering effective training.

The second component is the adaptation and implementation guide, which provides crucial information on customizing the caregiver training materials and delivery methods to suit local contexts. This guide emphasizes the importance of cultural and contextual adaptation in effectively implementing the training.[xxxii] The facilitators' guide is the third element in the package, offering comprehensive instructions for leading group sessions 1–9. It serves as a reference manual for facilitators and is designed to be used alongside specific training and supervision to ensure effective delivery.[xxxiii]

The participant's guide, the fourth component, is tailored for caregivers engaged in the training program. It includes illustrated key messages and strategies for each session, as well as activities to help caregivers set goals for their children.[xxxiv] Finally, the home visit guide for facilitators provides detailed information for conducting three home visits as part of the training. It includes objectives, activities, goal-setting forms, and troubleshooting tips to support caregivers in implementing learned skills in their home environments.[xxxv]

The WHO eLearning course on Caregiver Skills Training for Families of Children with Developmental Delays or Disabilities is also available online through Open WHO.[xxxvi]

The Health Care Access Research and Developmental Disabilities (H-CARDD) program's health care toolkit, Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers,[xxxvii] is designed to equip primary care providers with essential tools and resources to facilitate health checks for adults with developmental disabilities. The toolkit provides both clinical tools and implementation strategies to support the integration of health checks in clinical practice. It includes resources for raising awareness in clinics, such as staff engagement surveys, promotional campaigns, and email blasts. It also offers methods for identifying patients with developmental disabilities through screening, Electronic Medical Records keyword searches, and International Classification of Diseases code tracking. For practices aiming to formalize a health check program, the toolkit outlines strategies for proactive patient engagement, including sample phone scripts and booking alerts. At the point of care, the toolkit offers health check templates, systems reviews, and guidance on recognizing commonly missed diagnoses. It emphasizes the importance of updating patient profiles and creating coordinated care plans. Additional resources include information on local specialty services, financial resources, and educational videos. The toolkit also provides patient and caregiver resources, including handouts, internet links, and guidance on psychological assessments, as well as a transition toolkit to support individuals as they age.

In addition, the H-CARDD program's other health care toolkit, Improving Emergency Care for Adults with Developmental Disabilities: A Toolkit for Providers,[xxxviii] is designed to equip emergency care providers with practical tools to enhance care for patients with developmental disabilities (DD). It offers strategies for building awareness within healthcare settings, including staff engagement surveys, awareness campaigns, and process mapping to support successful implementation. The toolkit also provides methods for identifying patients with DD, including screening tools and the "About Me" tool, which helps communicate essential patient information.

In addition, the toolkit offers guidance on adapting clinical approaches, with resources such as a head-to-toe assessment, tip sheets for various healthcare staff, and communication strategies to accommodate patients' needs. There are also resources for environmental accommodation, rapid tranquilization, and educational videos to assist providers. For patients and caregivers, the toolkit includes resources like social stories, video guides, and helpful websites. Finally, it emphasizes the importance of enhancing discharge communication with exit interviews and preparations for future emergencies, aiming to improve the overall emergency care experience for adults with developmental disabilities.

The Abu Dhabi Early Childhood Authority's Communication Guide for Pediatric Healthcare Professionals[xxxix] focuses on enhancing the quality of interactions between healthcare providers and parents of young children who may face developmental delays or disabilities. It emphasizes the critical importance of sensitivity and empathy when delivering challenging news, outlining nine key principles to guide healthcare professionals through the communication process. These principles include creating a private space for discussions, using clear and simple language, inviting relevant support persons, allowing parents time to process information, confirming understanding, and encouraging active engagement from parents. The guide also underscores the need for ongoing support and collaboration, providing practical examples and resources to empower healthcare professionals to communicate effectively and compassionately.

ANALYSIS:

A) Core Areas Addressed by Global Clinical Guidelines for Individuals with IDD

The abovementioned guidelines and resources for individuals with IDD encompass several critical areas aimed at improving care, support, and overall quality of life. A holistic, person-centered approach to healthcare is advocated, integrating diverse sources of knowledge, including empirical research and patient experiences. Effective communication is emphasized to ensure that individuals and their caregivers are actively involved in the decision-making process, honoring their preferences and values. Tailored health assessments are encouraged for disease prevention and early detection, with personalized health action plans developed to address specific health needs.

The guidelines emphasize family involvement in care and the importance of comprehensive planning for life transitions to ensure appropriate support during major changes. Additionally, vigilant monitoring is mentioned to detect any signs of abuse, which can arise from various sources within the support network. Physical health recommendations include regular screenings for various conditions and the creation of individualized care plans that address preventive care and the management of existing health issues. Mental health is recognized as a critical aspect of overall well-being for individuals with IDD, with proactive strategies suggested to foster social networks and interpret challenging behaviors as indicators of underlying emotional distress. Recommended interventions encompass counseling, trauma-informed care, and careful medication management to effectively address mental health needs.

Assessment tools are available to evaluate the support needs of individuals across essential life domains, focusing on fostering independence rather than identifying deficiencies. Ethical frameworks for professionals are provided, emphasizing respect, integrity, accountability, and effective communication to safeguard the dignity and confidentiality of individuals. Training for professionals covers key areas such as philosophical understanding, practical skills, communication skills, team-building skills, and knowledge of available resources, encouraging professionals to recognize the dignity of individuals with IDD and view their behaviors as communication.

Additionally, training includes essential interventions like crisis management, trauma-informed care, and cultural sensitivity in treatment planning. Resources aimed at family caregivers address their unique challenges, providing practical information and strategies to enhance their well-being, with an emphasis on building support networks and protective factors to help them manage stress. A structured training program for caregivers enhances skills related to child engagement, communication, and daily living, featuring guides for adaptation to local contexts, facilitators' instructions for group sessions, participant resources for skill development, and effective home visit strategies.

Furthermore, the guidelines underscore the importance of cultural competency in healthcare, ensuring sensitive engagement with individuals and their families. Effective communication strategies are vital for building rapport and trust and facilitating better health outcomes. Lastly, the significant impact of trauma, stress, grief, and loss in the lives of individuals with IDD is recognized, with guidelines providing insights and strategies for addressing these complex experiences in therapeutic settings. Overall, the guidelines are comprehensive and aim to enhance the quality of life and support the unique needs of individuals with IDD, and their families.

The guidelines and resources for individuals with IDD are designed for a diverse audience, encompassing children and adults with IDD, with a strong emphasis on inclusivity across all genders. The primary focus is on parents, guardians, and family members, who play a crucial role in advocating effective care strategies. Additionally, professional caregivers such as nurses, social workers, therapists, and educators are highlighted for their direct influence on the quality of support provided. In contrast, interested parties, including non-profit organizations, policymakers, and advocacy groups, are acknowledged, but given less emphasis in the guidelines.

A) Identified Gaps in Global Clinical Guidelines for IDD

The existing guidelines for individuals with IDD provide valuable frameworks and resources that help support individuals and their families. However, compared to the more developed guidelines for autism, fewer guidelines are available for IDD, and significant gaps remain. Addressing these gaps could help improve the support and resources available, ultimately enhancing the quality of life for individuals with IDD and their families.

Failure To Account for the Diverse Needs of Healthcare Professionals in Various Environments. In rural and Indigenous communities, caregiving is often deeply rooted in local traditions, and resources are limited. In these settings, the emphasis should be on strengthening and enhancing existing care practices rather than introducing new, complex approaches. Conversely, urban areas with well-established healthcare systems may require more specialized training in advanced care techniques, a need that the guidelines do not address in detail. Additionally, the guidelines fail to adequately address the needs of cultural, linguistic, and ethnic minority groups with IDD, for whom equity in healthcare access and quality is also a significant concern.

Western Focus. A key limitation of many existing guidelines is their reliance on research conducted in high-income Western countries, which introduces a cultural bias that overlooks the specific challenges faced by low- and middle-income countries. This makes the guidelines less applicable in a global context, especially in regions with different cultural, socioeconomic, and infrastructural realities. For example, guidelines designed for urban areas may not be effective in rural, and under-resourced settings where healthcare systems are still developing, and caregiving is often community-based and informal.

Lack of a Centralized Platform for Resources and System Navigation. This makes it difficult for professionals and caregivers to find the information they need quickly. Instead, they waste valuable time searching across multiple platforms, time that could be better spent on caregiving. Furthermore, many existing guidelines and tools use complex language and technical terms that can be difficult for non-professional caregivers and even some healthcare professionals to understand. For instance, a caregiver may find it challenging to interpret medical terminology, which can hinder their ability to apply the guidelines effectively in their caregiving.

Challenges in Accessing Up-to-Date and Affordable IDD Care Guidelines. Many guidelines are not updated regularly; hence they may lack the latest research or evidence-based practices relevant to IDD care. As a result, caregivers and professionals might rely on outdated information, limiting the quality of care they can provide. To make matters more challenging, many resources are not available for free and are behind paywalls or priced in dollars, making them unaffordable, especially in low- and middle-income countries where the demand for these resources could be highest.

Gaps in Transition Planning, Integrated Care, and Follow-Up Support for Individuals with IDD. Guidelines lack comprehensive strategies for supporting individuals with IDD through significant life transitions, such as from childhood to adulthood, or from school to work. Targeted resources on transition planning and support are necessary, especially considering the aging population, in areas where specific geriatric care needs may not be adequately addressed. Furthermore, currently, mental health and physical health care guidelines for individuals with IDD are often treated separately, which creates a fragmented approach to care. This division overlooks the co-occurrence of mental health issues, like anxiety and depression, with physical health challenges in individuals with IDD, leading to missed opportunities for integrated care. In addition, while the guidelines emphasize the importance of regular health screenings for individuals with IDD, there is often no clear pathway for follow-up care after screening. This lack of guidance leaves individuals without the necessary support, highlighting the need for integrated care models that ensure timely and accessible treatment.

Communication Barriers in IDD Care and Support. Individuals with IDD have diverse communication styles, which can make it difficult for them to express their needs verbally. Despite these differences, it is crucial to consider their perspectives when creating care models that truly reflect their experiences. While there are guidelines on how to communicate effectively with people with IDD, these guidelines often take a backseat to clinical topics. For instance, healthcare providers may focus more on medical treatment than on how to interact with individuals in a way that is accessible to them. Additionally, there is a lack of clear guidance on how to adapt communication strategies for individuals with different levels of communication skills and across various age groups. For example, a child with IDD may require a different communication approach than an adult with the same diagnosis. This oversight highlights the importance of recognizing communication as a key factor in providing effective support for individuals with IDD.

Limited Direct Engagement with Individuals with IDD in Care Planning. Current care approaches tend to rely heavily on input from caregivers rather than directly engaging with individuals with IDD. While caregivers provide valuable insights, depending too much on them limits understanding of the unique needs and experiences of individuals with IDD themselves. For instance, a caregiver might explain a person's needs based on their interpretation, but this might not fully capture the individual's preferences or feelings. If we do not prioritize the voices of those directly affected, care strategies may not meet their actual needs, leading to ineffective or misguided interventions.

Lack of Trauma-Informed Care in IDD Healthcare Settings. There is a clear gap in integrating trauma-informed care for individuals with IDD, despite their increased vulnerability in healthcare settings. Many have experienced past trauma, including stressful medical procedures, yet current guidelines often overlook several aspects of this. For example, a person with IDD who had a traumatic medical experience may feel anxious during future visits, but there's limited guidance on addressing these concerns. Additionally, healthcare environments often fail to account for the emotional and psychological needs of individuals with IDD. Sensory sensitivities or difficulty communicating discomfort can lead to heightened stress, yet trauma-informed care practices that could help are rarely applied. This leaves individuals at risk of re-traumatization and greater anxiety during medical encounters.

Lack of Suicide Prevention and Emergency Crisis Response for Individuals with IDD. The current guidelines do not adequately address suicide risk among individuals with IDD. The unique challenges faced by people with IDD, such as communication difficulties, social isolation, and mental health struggles, make them more vulnerable to suicide. However, these factors are often overlooked in existing care models, leaving a critical gap in suicide prevention and intervention for this population. Furthermore, there is a lack of comprehensive guidance on emergency care and crisis response for individuals with IDD, particularly during natural disasters. These individuals are at greater risk during such events due to challenges in communication, mobility, and accessing appropriate support. Existing protocols often fail to account for their specific needs, leaving them vulnerable in emergencies.

Insufficient Support for Puberty, Sexuality, and Reproductive Health for Individuals with IDD. Topics such as puberty, sexuality, and reproductive healthcare choices are often underexplored in existing support frameworks for individuals with IDD. As individuals with IDD go through puberty, they may encounter challenges in understanding bodily changes, managing new emotions, and developing relationships. Additionally, they may face difficulties in making informed decisions about reproductive health. Despite the significance of these issues, many current resources, guidelines, and care tools fail to address these topics in an accessible manner. This gap in support leaves individuals with IDD and their caregivers without the guidance needed.

Insufficient Support for Caregivers' Emotional and Practical Needs. Caregiving can place a significant emotional and psychological load on families, especially on parents and siblings. While some resources exist to support them, these often fall short of addressing their full range of needs such as coping with stress, managing caregiver burnout, navigating financial challenges, and balancing caregiving responsibilities with personal and professional life. There is also a noticeable lack of support for extended family members, who frequently take on caregiving responsibilities but are often overlooked in existing programs. Additionally, many guidelines do not provide enough training or resources to support professional caregivers in managing their emotional and physical well-being, leaving them unprepared to handle the challenges of their roles effectively.

Barriers to Accessing Community Resources and Support Systems. Strong community connections are important for fostering inclusion and independence. However, current guidelines often fail to link individuals with IDD and their families to essential local resources, such as support networks, recreational activities, and employment opportunities. Community integration ensures that individuals with IDD can actively participate in society, build meaningful relationships, and develop skills that enhance their quality of life. By promoting autonomy and inclusion, a well-connected support system empowers individuals to navigate their environments with confidence and lead fulfilling lives.

Challenges in Accessing Policy and Funding Support. Navigating complex policy and funding systems remains a significant challenge. Many families struggle to understand the legal processes and funding mechanisms needed to access critical services like therapy, respite care, or specialized education programs. This lack of clarity can result in delayed or inadequate care.

Limited Integration of Technology Particularly in Reaching Underserved Populations. As technology increasingly plays a vital role in healthcare and education, there is also a notable gap in guidelines on effectively incorporating technology into the care and support of individuals with IDD. For example, assistive technologies like communication devices, virtual learning platforms, or telehealth services could dramatically improve access to care, yet there is little guidance on how to integrate these tools into everyday care routines. Finally, while interested parties such as non-profit organizations, policymakers, and advocacy groups are acknowledged in some guidelines, they often receive insufficient emphasis. These groups are crucial in shaping policy, advocating resources, and providing services to individuals with IDD, but their role is not always fully integrated into care models.

Global Health Disparities in Developmental Disabilities Care. A global report[xl] by the WHO and UNICEF underscores the pressing need to tackle health disparities affecting individuals with developmental disabilities worldwide. This population includes an estimated 317 million children and young people, highlighting the global scale of the issue. The report emphasizes that individuals with developmental disabilities frequently face stigma, social exclusion, and substantial barriers to accessing quality healthcare. These challenges contribute to poorer health outcomes and an increased risk of premature mortality. It highlights common underlying conditions associated with developmental disabilities, including autism, intellectual developmental disorders, attention-deficit hyperactivity disorder, and various other neurodevelopmental conditions. Additionally, the report underscores how fragmented healthcare systems exacerbate unmet health needs, further compounding the challenges faced by this population.

It is also important to note that many individuals with IDD do not receive the services they need. For those who do, outcomes tend to be more positive across several key areas. This underscores the need to expand access to services and support for all individuals with IDD.

RECOMMENDATIONS

While existing clinical guidelines and standards of care for individuals with IDD provide a solid foundation, there remains significant room for improvement to better address their unique needs. Identified gaps in global guidelines and related resources present valuable opportunities to enhance support for individuals with IDD worldwide. Addressing these gaps requires comprehensive strategies that consider the diverse needs of all interested parties, including individuals with IDD, their families, healthcare professionals, and community support systems. The following section explores key opportunities for improving IDD care, emphasizing the creation of accessible, culturally sensitive and effective support structures to meet the needs of the global IDD community.

	Gaps in IDD Care Guidelines and Similar Resources	Recommendations
Cultural and Environmental Considerations Gaps		
1	**Limited Resources and Guidelines for IDD:** Globally there are fewer comprehensive frameworks, tools, and training resources for IDD compared to conditions like autism. This leads to inconsistent care practices and a lack of clear guidance for caregivers and healthcare providers, making it harder to offer effective support to individuals with IDD.	**Forming Global Communities of Practice (CoP) for IDD:** To address the lack of comprehensive frameworks and resources for IDD, establishing Global Communities of Practice (CoPs) could provide an effective solution. These CoPs would bring together caregivers, healthcare providers, practitioners, individuals with IDD, and their families from diverse cultural and geographical backgrounds. By fostering collaboration and sharing knowledge, experiences, and best practices, these communities would help bridge the knowledge gap and improve care for individuals with IDD. Additionally, members of these communities would document their shared insights and resources, contributing to the creation of a global repository platform. This platform would compile valuable guidelines, training materials, and practical strategies in an easily accessible format, ensuring that individuals, families, and professionals worldwide have access to the tools and support they need to provide effective and person-centered care.
2	**Intersectionality and Cultural Bias in IDD Care Guidelines:** Current IDD care guidelines often overlook the intersectionality of factors such as race, socioeconomic status, and gender identity, as well as the cultural and regional variations that shape the experiences of individuals with IDD. Many of these guidelines are based on research from high-income Western countries, which makes them less applicable to low- and middle-income regions with distinct cultural,	**Addressing Intersectionality and Cultural Bias through Global Communities of Practice (CoP):** The formation of Global Communities of Practice (CoPs) could significantly address the issue of intersectionality and cultural bias in IDD care guidelines. By bringing together diverse stakeholders including caregivers, healthcare providers, individuals with IDD, and their families, from various cultural and regional backgrounds, CoPs could create a platform for sharing local knowledge and experiences. This collaborative exchange could help bridge the gap between Western-centric research and the needs of individuals in low- and middle-income countries,

	economic, and infrastructural challenges. This gap limits the development of inclusive, equitable, and effective care strategies that can adequately address the diverse needs of individuals with IDD around the world.	where cultural, socioeconomic, and infrastructural factors may differ widely. Through CoPs, participants could document their unique care strategies, challenges, and successes, contributing to the development of more inclusive and culturally sensitive care guidelines. Moreover, CoPs could offer post-publication peer review on existing guidelines, helping to make them more relevant to diverse audiences by incorporating input from a wide range of cultural, economic, and regional perspectives.
3	**Failure to Address Diverse Healthcare Environments and Audiences:** Healthcare practitioners in rural, remote, and indigenous community areas often struggle to adapt urban-centric guidelines to suit local traditions, values, and the limited resources available. These guidelines are typically designed with urban settings in mind, making them less relevant or feasible in rural, remote and indigenous community areas. Meanwhile, healthcare professionals in urban environments may not receive specialized training in advanced care techniques needed to address the unique needs of individuals within their communities.	**Developing Regional Care Models with Local Input:** Developing region-specific, culturally tailored care guidelines for individuals with IDD is one potential way to ensure more effective support. These guidelines should be shaped through collaboration with healthcare providers, community leaders, and Indigenous groups, accounting for local customs, resources, and infrastructure. Alongside these localized guidelines, specialized training programs for healthcare providers in both urban and rural settings could address the unique needs of each population. Training programs could be designed to reach both regions with and without internet access, utilizing a mix of in-person and offline methods. In areas with reliable internet, online courses, webinars, and virtual workshops would offer flexible learning opportunities. In remote areas, mobile training units could provide in-person workshops, while printed materials could support the implementation of best practices among healthcare providers
4	**Overlooking the Use of Existing Resources for Early Detection and Care in Under-Resourced Areas:** Many guidelines often neglect how to effectively utilize existing community resources to support the early detection	**Integrating IDD Screening into Existing Public Health Programs:** A key strategy for the early identification of IDD in under-resourced areas could be incorporating IDD screening into established public health programs, such as vaccination or maternal-child health visits. This approach would help

	and care of individuals with IDD in under-resourced areas.	reach a wider population and ensure the timely detection of disabilities. By utilizing existing healthcare touchpoints, logistical barriers can be minimized, and routine screenings can be conducted without requiring additional infrastructure. Furthermore, training healthcare providers at these touchpoints to recognize the early indicators of IDD would allow for prompt referrals for further assessment and support. Including IDD screening in regular check-ups can also normalize the process, making it less daunting for families and improving participation rates. **Training Non-professional Caregivers:** Training non-professional caregivers, particularly parents, to identify early signs of IDD and provide basic interventions is essential. Empowering caregivers with these skills can greatly improve early detection and support, even in areas with limited access to specialists. **Building Community-Based Support Networks:** Community-based support networks can improve care for individuals with IDD in under-resourced areas by connecting caregivers to share experiences and resources. For example, in rural areas, parent groups meet regularly to exchange tips, local therapy options, and support. These networks can work with local clinics to ensure families have access to services and ongoing support. **Leveraging Technology to Enhance IDD Support and Screening:** In areas with reliable internet access, tech tools such as mobile apps, telemedicine, and online platforms can provide affordable solutions for screening and ongoing support. In regions with limited technology, SMS-based programs or phone consultations can still deliver essential guidance and resources to help families and caregivers.

5	**Complexity of Language and Terminology:** Caregivers, especially those without a professional background, often find the medical language and technical terms used in existing guidelines difficult to understand and apply effectively, which can hinder their ability to provide optimal care.	**Translation-Focused Multilingual Resource Platform:** A platform could be created to provide care guidelines for individuals with IDD in multiple languages, helping caregivers from different backgrounds. The platform could use simple and clear language while keeping important medical terms accurate. For difficult words, it could offer clickable definitions or explanations. Visual aids, infographics, and real-life examples could be included to make the guidelines easier to understand. Local translations could ensure the content fits different regions and respects cultural differences and local practices.
Accessibility and Affordability Gaps		
1	**Lack of a Centralized Platform and Inconsistent Updates to IDD Guidelines:** Caregivers and practitioners often struggle to access up-to-date IDD care guidelines due to the absence of a centralized platform. This lack of centralized access, combined with irregular updates to guidelines, prevents the integration of the latest evidence-based practices, limiting the quality of care provided to individuals with IDD.	**Centralized Global Repository Platform for IDD Care:** A global platform, developed through collaboration with organizations like the WHO, national health agencies, academic institutions, and caregiving groups, could serve as a central hub for IDD care. It could provide real-time updates on the latest research, treatment options, and best practices. The platform could automatically notify caregivers and professionals about new strategies, such as effective interventions for managing co-occurring conditions in individuals with IDD. Subscribing to the platform would help caregivers and healthcare providers stay up to date on the most effective approaches to care, ensuring continuous access to current information and support. To improve the platform's accessibility, it could be designed with a clear, user-friendly structure that enables users to easily search for and navigate relevant content. The platform could include sections with guidelines, success stories, and best practices, organized around themes like cultural sensitivity and the distinct needs of rural versus urban contexts. Additionally, it could promote collaboration by

		allowing users to share experiences, seek advice, and brainstorm new ideas. The goal would be to create a supportive, easily navigable space that fosters ongoing learning, builds a sense of community, and drives continuous improvement in IDD care.
2	**Limited Affordability and Accessibility:** Many IDD care resources and guidelines are published in journals or on websites that require expensive memberships or fees for access, making them unaffordable, especially in low- and middle-income countries. This limits access to essential resources for caregivers and practitioners who need them most, further exacerbating challenges in providing quality care due to the high costs.	**Open-Access to Centralized Global Repository Platform:** The proposed global platform could provide free or low-cost access to essential guidelines to provide a solution to the issues of limited affordability and accessibility. Funded by international organizations and governments, this hub could offer free access to comprehensive resources, including guidelines, research, training materials, and best practices, tailored for caregivers, healthcare providers, and practitioners, especially in underserved regions such as low- and middle-income countries. By eliminating the costs associated with memberships or subscriptions, this initiative would ensure that vital information is accessible to all, regardless of financial constraints. Support for this platform could come from collaborative efforts among global agencies and national governments committed to advancing equitable care for IDD.
Care Continuity and Coordination Gaps		
1	**Inadequate Support for Life Transitions for Individuals with IDD:** Individuals with IDD often face challenges during key life transitions, such as moving from school to work or aging into adulthood, due to a lack of tailored support and guidance. This gap leaves them, and their caregivers, without the necessary resources to navigate these critical milestones effectively.	**Community-Based Transition Hubs:** Community-based transition hubs could serve as essential one-stop centers for individuals with IDD, providing comprehensive support as they transition to adulthood. These hubs could offer workshops and group sessions focused on life skills, socialization, employment, and financial literacy, creating a hands-on, collaborative learning environment. Additionally, the hubs could partner with local businesses to provide job readiness training, simulate real-world work experiences, and offer internships, volunteer opportunities, and job placement services tailored to each individual's unique

		skills and interests. To further support families and caregivers, these centers could also provide workshops, counseling, and resources to ensure they are well-equipped to assist their loved ones during the transition process.
2	**Lack of Support for Specific Daily Needs of Individuals with IDD:** Current guidelines often fail to address the basic daily needs of individuals with IDD. While broader aspects of their lives are somewhat supported, there is a significant gap in meeting individualized needs like personal hygiene, meal preparation, light household chores, using public transportation, managing small amounts of money, and engaging in social activities. Existing guidelines tend to focus on generalized care, and this gap in support can leave individuals and their families without the necessary resources to manage fundamental tasks, affecting their independence and quality of life.	**Personalized Daily Support Toolkits (with Physical and Digital Tools):** To address the daily needs of individuals with IDD, personalized support toolkits could be created that outline specific tasks like personal hygiene, meal preparation, and managing money. For areas with internet access, a digital app could be developed that uses visual schedules, reminders, and step-by-step instructions to guide users through these tasks. In places without internet access, these toolkits could be provided in the form of printed checklists and visual prompts, helping individuals and caregivers structure their daily routines effectively. These toolkits could be shared on a global open-access resource hub for IDD care, allowing caregivers, professionals, and families around the world to access, download, and customize the resources to meet the needs of individuals in various contexts. **Community-Based Life Skills Coaching:** Community-based life skills programs could be created to provide in-person coaching for daily living tasks such as cooking, personal care, and budgeting. These programs could be created through local community centers or schools and involve local volunteers or professionals who guide individuals with IDD through practical lessons. By offering hands-on workshops and real-life practice, these programs could help individuals gain the confidence and skills needed for independence, even in areas with limited resources or internet access.

3	**Fragmented Approach to Mental and Physical Health:** Practitioners often face challenges in providing coordinated care for individuals with both mental and physical health needs, leading to fragmented approaches to treatment.	**Integrated Health Care Teams and Global Guidelines:** To address the fragmented approach to mental and physical health care, global integrated healthcare teams could be formed, consisting of medical professionals, mental health practitioners, and specialists. These teams could develop comprehensive guidelines for integrated care, focusing on the combined treatment of both physical and mental health needs for individuals with IDD. Once these global guidelines are established, each country or region could form local teams to adapt and implement these standards based on their unique cultural, societal, and resource-related contexts, ensuring that the care provided is relevant and effective. **Unified Health Record System for Coordinated Care:** In addition to the global guidelines, a unified health record system could be implemented by each country or region to centrally track the physical and mental health treatments of individuals with IDD. This system could be designed to function in both online and offline environments. For regions with internet access, the system could enable real-time sharing of data between team members, enhancing communication and care coordination. In areas without internet access, paper-based records could be used. This might lead to more coordinated, comprehensive, and accessible care for individuals with IDD.
4	**No Clear Pathway for Follow-Up Care after Screening:** Practitioners and caregivers lack guidance on follow-up steps after screenings, leaving individuals with IDD without consistent care and support.	**Developing Post-Screening Support Guidelines for Practitioners and Caregivers:** With input from experts globally, comprehensive post-screening support guidelines could be developed to assist both practitioners and caregivers in managing the next steps after an IDD screening. These guidelines would provide a clear roadmap for recommended evaluations, therapies, and interventions tailored to the individual's specific needs. A structured timeline

		could be included to ensure timely and appropriate follow-up, guiding caregivers through the process of accessing services and scheduling necessary appointments. To enhance accessibility and understanding, clear, concise one-page documents can be created, incorporating infographics to simplify complex information. Additionally, the guidelines could offer practical advice on managing day-to-day care, such as strategies for handling behavior challenges, establishing routines, and fostering skill development. These guidelines would empower caregivers and equip practitioners to deliver coordinated and effective care. **Community Health Worker Involvement and Accessibility:** Community health workers could play a key role in the successful implementation of post-screening support guidelines by taking an active role in monitoring progress and offering personal support. These workers could be tasked with scheduling follow-up visits or phone calls to check on the individual's development and address emerging concerns as needed. To ensure that the support reaches as many individuals as possible, the guidelines could be made widely accessible through digital platforms, local health centers, and caregiver networks. This could ensure that all parties involved, whether in remote areas with limited access to healthcare or urban centers with more resources, have the necessary tools and ongoing support to improve the care of individuals with IDD.

Communication and Support Gaps		
1	**Limited Adaptation to Diverse Communication Styles:** Communication strategies are often not prioritized in guidelines, despite being central to supporting individuals with IDD. The focus is more on clinical treatment than communication needs. In addition, caregivers and practitioners often struggle to effectively address the varied communication needs of individuals with IDD due to a lack of appropriate tools and strategies.	**Conduct Global Research to Identify Communication Needs:** It could be beneficial to initiate a global research effort involving experts, caregivers, and individuals with IDD to understand the diverse communication styles and challenges faced worldwide. By gathering insights from various cultures and contexts, the findings could lay the foundation for designing inclusive and adaptable communication tools. **Develop Guidelines, Toolkits, and Training Modules:** Based on the research mentioned above, a set of culturally sensitive guidelines and toolkits could be developed to address the unique communication needs of individuals with IDD. It is important to expand the definition of communication needs to include difficulties in understanding nonverbal cues, such as facial expressions, and body language, challenges that many individuals with IDD face. Additionally, training modules could be created to equip caregivers with the skills to use these tools effectively. **Deliver Training Using Online and Offline Methods:** Training for caregivers could be delivered through a hybrid approach. In areas with internet access, virtual platforms could be utilized to conduct interactive sessions, while in regions without connectivity, in-person workshops facilitated by local organizations could be an effective alternative.

2	**Limited Guidance on Adapting Communication Strategies for Different Life Stages in IDD:** Current care guidelines often lack clear direction on how communication strategies should evolve as individuals with IDD progress through different life stages. As a person with IDD develops or their needs change, the methods of communication that worked at one stage may no longer be effective at another. Without guidance on adjusting communication approaches based on age, development, or changing abilities, caregivers and practitioners may find it difficult to connect in meaningful ways, therefore hindering the individual's ability to express themselves and engage more productively.	**Conduct Research on the Transition Needs of Individuals with IDD:** Research could be done to understand the transition needs of individuals with IDD as they move through different stages of life. This research could involve input from global experts, caregivers, and individuals with IDD to ensure the findings reflect a variety of needs and cultural contexts. **Design the Adaptive Communication Curriculum with Cultural Sensitivity:** Based on the research, an adaptive communication curriculum could be developed for caregivers, focusing on adjusting communication strategies based on age and the evolving needs of individuals with IDD. The curriculum could include scenario-based training, videos, and role-playing exercises. It would also incorporate insights from global experts to ensure it includes the best practices from around the world and is culturally sensitive. **Implement and Deliver the Curriculum:** The curriculum could be delivered via both online and offline methods. In areas with internet access, it could be made available through online platforms, while in regions with limited internet, offline resources like printed materials or local workshops could be used to train caregivers effectively.
3	**Neglecting the Voice of Individuals with IDD in Communication Strategies:** Currently, care strategies often rely too heavily on caregiver interpretations of an individual's needs, which can result in overlooking the preferences, feelings, and personal communication styles of individuals with IDD. This approach fails to fully	**Developing Person-Centered Communication Tools for Individuals with IDD:** Person-centered communication boards and apps can be valuable in helping individuals with IDD express their preferences, such as in activities and foods, or their emotions, through visual symbols and pictures. Caregivers can assist by guiding individuals to select or point to images that represent their choices. For example, a communication board may include pictures

	acknowledge the importance of directly involving individuals with IDD in decisions about their communication methods.	of activities like reading, walking, or eating, enabling the individual to clearly communicate their desires without relying solely on the caregiver's interpretation. Additionally, it is essential to create separate communication tools for individuals who are hard of hearing or visually impaired. These tools could include sign language or visual aids for individuals with hearing challenges, and braille or audio descriptions for those with visual impairments, to ensure effective support for all individuals.
Trauma and Crisis Management Gaps		
1	**Lack of Trauma-Informed Care:** Practitioners often lack training in trauma-informed approaches, making it harder to provide emotionally sensitive care for individuals with IDD who have experienced trauma.	**Development of Global Guidelines for Trauma-Informed Care:** To address the lack of trauma-informed care, global guidelines could be developed in collaboration with experts. These guidelines would provide clear protocols for caregivers and practitioners on how to identify and respond to trauma in individuals with IDD. The guidelines could focus on recognizing trauma-related behaviors, understanding the emotional and psychological impacts of trauma, and creating safe and supportive environments that promote healing. **Creation of Training Modules with Emphasis on Holistic Support Systems:** Training modules could be developed to equip caregivers and practitioners with the necessary skills to implement trauma-informed care effectively. These modules could include practical strategies for recognizing trauma signs, understanding behavioral cues, and fostering emotionally supportive environments. Additionally, the training could emphasize the importance of creating a holistic support system that involves not only the direct care providers, but also community resources, peer support networks, and access to mental health professionals who specialize in trauma-informed care. This network of support could reduce isolation, prevent burnout, and ensure long-term resilience for both individuals and caregivers.

2	**Risk of Re-Traumatization in Healthcare Settings:** Caregivers and practitioners often lack guidance on how to prevent sensory and emotional triggers during medical visits, leading to potential re-traumatization.	**Global Sensory-Friendly Guidelines for Healthcare Facilities:** A comprehensive set of global guidelines could be developed to help healthcare facilities create sensory-friendly environments that reduce the risk of re-traumatization for individuals with IDD. These guidelines would provide practical recommendations on modifying key environmental factors such as lighting, noise levels, and spatial layout to minimize sensory overload. Additionally, the guidelines could include staff training modules focused on recognizing potential triggers, understanding sensory sensitivities, and using trauma-informed communication techniques.
3	**Inadequate Suicide Risk Prevention:** Practitioners and caregivers are not equipped to identify or address suicide risk factors unique to individuals with IDD.	**Suicide Risk Identification Toolkit for Individuals with IDD:** A global Suicide Risk Identification Toolkit could be developed specifically for caregivers and practitioners working with individuals with IDD. This toolkit would offer tailored screening questions that cater to various communication styles, ensuring that individuals with different abilities can be appropriately assessed for suicide risk. It would also include practical strategies for managing and mitigating risk, such as recognizing early warning signs, establishing supportive environments, and utilizing coping mechanisms that work for individuals with IDD. **Suicide Prevention Training for Local Caregivers and Practitioners:** A localized training program could be developed for caregivers and practitioners to enhance their ability to identify and address suicide risks in individuals with IDD. This training would focus on recognizing signs of emotional distress, understanding the unique challenges individuals with IDD face, and teaching communication techniques for sensitive conversations about mental health and suicide. The training could be tailored to local contexts, delivered through community-based workshops or support groups, and made accessible in both in-person sessions and through local community

		centers. **Peer Support Networks and Community Involvement:** Peer support networks can be created where individuals with IDD, along with their families and caregivers, can connect with others facing similar challenges. These networks could offer mutual support and thus reduce feelings of isolation, which is a significant risk factor for suicide.
4	**Lack of Comprehensive Emergency and Crisis Care Guidance:** Caregivers and practitioners face challenges during crises, such as natural disasters, due to the absence of emergency protocols tailored for individuals with IDD.	**Global IDD Crisis Care Protocols:** A set of comprehensive crisis management protocols could be developed specifically for emergencies, such as natural disasters or pandemic health crises. These protocols would provide first responder professionals, caregivers, and practitioners with clear, practical guidelines on how to prepare for and respond to emergencies. The protocols would include practical tools such as checklists, emergency contact forms, and evacuation plans tailored to the specific needs of individuals with IDD. These could be adapted by different countries, taking into account local resources, communication methods, and specific emergency practices. **Localized Crisis Preparedness Workshops and Training:** In addition to the development of global protocols, localized workshops and training programs could be implemented to help first responder professionals, caregivers, and practitioners prepare for emergencies. These workshops could focus on educating how to create personalized emergency plans for individuals with IDD, including strategies for communication during crises, managing anxiety, and ensuring physical safety. The training could also include information about local resources, such as shelters, and offer practical activities to help participants practice handling emergencies.

<table>
<tr><th colspan="3">Sexual Well-Being Gaps</th></tr>
<tr><td>1</td><td>Underexplored Topics of Puberty, Sexuality, and Reproductive Healthcare Choices: Caregivers lack resources to support individuals with IDD in understanding and managing changes related to puberty, sexuality, reproductive healthcare choices, and relationships.</td><td>IDD Puberty, Sexuality, and Reproductive Healthcare Choices Education Program: A comprehensive, interactive educational platform could be created to provide resources for caregivers and individuals with IDD on puberty, sexuality, and reproductive healthcare choices. This platform could feature expert-led webinars, informative videos, and interactive modules, all designed to be age-appropriate and tailored to various developmental stages. It would equip caregivers with clear, practical tools and guidance to support individuals with IDD through these sensitive topics, helping them navigate discussions on sexuality and relationships in a respectful and well-informed manner.

Customized Educational Toolkits for Caregivers: A toolkit specifically designed for caregivers could be developed, containing step-by-step guides, conversation starters, visual aids, and real-life scenario examples for discussing topics related to puberty, sexuality, and relationships with individuals with IDD. These toolkits could be adapted to different cognitive abilities and could include various formats (written, visual, or audio) to cater to individual learning styles.

Incorporating Sexuality Education into Existing IDD Programs: Sexuality and relationship education could be integrated into existing IDD training programs or curricula, ensuring that these topics are discussed regularly as part of the overall care and education plan. This could include incorporating lessons on consent, personal boundaries, emotional regulation, and safe relationships into general life skills programs, making them a part of daily learning.</td></tr>
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Caregiver Training and Support Gaps		
1	**Insufficient Training and Support for Professional Caregivers:** Professional caregivers often lack the necessary training and resources to effectively address the unique challenges faced by individuals with IDD, while also managing the physical and emotional demands of caregiving for themselves.	**Comprehensive Training Programs for Professional Caregivers:** A comprehensive, specialized training program could be developed to equip professional caregivers with the necessary skills and knowledge to manage the unique needs of individuals with IDD. This training could cover areas like communication strategies, understanding challenging behaviors, emotional regulation, and practical caregiving techniques. In addition, the program could include modules on self-care, stress management, and emotional resilience to help caregivers manage the physical and emotional demands of their roles. **Development of Caregiver Resource Toolkits:** A caregiver resource toolkit could be created to provide professional caregivers with practical tools, guidelines, and strategies to address the challenges of caregiving. The toolkit could include emergency protocols, communication tips, behavioral management techniques, and resources for managing caregiver stress. These toolkits could be distributed regularly, and caregivers could be encouraged to adapt and personalize them to suit the unique needs of the individuals they care for. **Ongoing Mentorship and Peer Support Networks:** To provide continuous support, mentorship programs could be implemented, where experienced caregivers guide and mentor those who are new or struggling with the demands of caregiving. Additionally, peer support networks could be established, either virtually or in-person, allowing professional caregivers to connect with others in similar roles. These networks would provide a platform for sharing strategies, experiences, and emotional support, reducing feelings of isolation and burnout.

2	**Emotional and Psychological Load on Caregivers:** Primary caregivers often experience high levels of stress, burnout, and financial strain due to the challenges of supporting individuals with IDD. Existing guidelines and toolkits often fail to adequately address or explore these issues in depth, leaving caregivers without sufficient support to manage these ongoing emotional and psychological burdens.	**Specialized Training for Caregivers:** Specialized training could be designed for caregivers to focus on stress management, self-care, and emotional resilience. This training could help caregivers recognize the signs of burnout, learn how to set healthy boundaries and develop coping strategies to manage the emotional challenges of caregiving. Interactive modules or workshops could be offered regularly, giving caregivers practical tools to manage their emotional well-being while providing care. This training could be delivered via a variety of formats, ensuring accessibility for caregivers in diverse regions, both with and without internet access. **Comprehensive Caregiver Support Programs:** A comprehensive caregiver support program could be developed, offering a combination of emotional, financial, and practical assistance. These programs could provide access to counseling, stress management workshops, and peer support groups where caregivers can share experiences and coping strategies. These programs could be made accessible both in-person and online to reach caregivers in different settings. **Global Caregiver Support Network with Local Chapters:** A global caregiver support network could be established, with local chapters to connect caregivers of individuals with IDD. These local chapters could foster a sense of community, allowing caregivers to share experiences and find support in a culturally relevant context. The network could offer access to professional counseling services to help manage stress and burnout, as well as expert guidance on practical matters such as financial planning and caregiving strategies.

2	**Neglect of Extended Family Support:** Extended family members often play a significant role in caregiving but are frequently overlooked in existing guidelines and tools which do not provide them with adequate training or resources.	**Inclusion in Caregiver Training Programs:** Extended family members could be included in existing caregiver training programs to ensure they have the knowledge and skills needed to provide effective care. These programs could offer flexible, family-friendly formats (online, workshops, or community sessions) to help extended families understand the specific needs of individuals with IDD. Training could cover key areas like communication strategies, emotional support, and how to manage challenging behaviors.
Barriers Addressable Through Policy Initiatives		
1	**Lack of Awareness and Stigma Around IDD:** In many low- and middle-income countries and communities, there is not enough awareness or resources for IDD. This lack of knowledge can cause delays in diagnosing IDD and prevent individuals from getting the support they need. Additionally, the stigma surrounding these disabilities can make things worse, leading to social isolation, discrimination, and limited access to proper care and services.	**Raising Awareness and Promoting Inclusion for IDD:** Governments can help raise awareness about IDD by launching nationwide campaigns. These campaigns can focus on the importance of early diagnosis and the benefits of early support. By using the media, schools, community groups, as well as local grassroots advocacy groups, governments can encourage understanding and acceptance of individuals with IDD. Policies can also be created to train healthcare workers, teachers, and social workers to better support people with IDD. Inclusive policies for schools, workplaces, and public spaces can help reduce discrimination and make society more accessible for everyone. **Promoting IDD-Friendly Services:** Governments can encourage the development of IDD-friendly services and products by incorporating such initiatives within their own institutions. For example, they can create sensory-friendly spaces in public facilities or support the use of assistive technology in government-run programs. By setting an example, governments can promote inclusivity and accessibility and encourage private companies and other organizations to follow suit.

		Supporting Local Organizations and Workforce Inclusion: Governments can support local organizations that help people with IDD by providing funding, grants, or tax breaks. These resources can improve access to important services like early intervention programs, therapy, and support groups. To help people with IDD join the workforce, governments can encourage companies to offer jobs, internships, and mentorships. This support could create more inclusive job opportunities and help individuals with IDD contribute meaningfully to their communities.
2	**Lack of Resources and Guidelines for IDD:** There are fewer resources, guidelines, and training for IDD compared to conditions like autism. This results in uneven care practices and confusion for caregivers and healthcare providers, making it difficult to provide effective support for people with IDD.	**Developing Dedicated Resources and Guidelines:** Governments can help in the development of comprehensive, evidence-based guidelines specifically for IDD, focusing on strategies for diagnosis, care, and intervention. They could also allocate funding for dedicated training programs for healthcare providers, educators, and caregivers. This could lead to more consistent and informed support for individuals with IDD, reducing disparities in care practices. **Integrating IDD into Existing Services:** Governments can introduce policies that integrate IDD-specific training and resources into existing healthcare, education, and social service systems. For example, healthcare providers could include IDD-related modules in their training, and schools could adapt special education programs. This approach could lead to improved accessibility and support without requiring entirely new systems. **Building Cross-Sector Collaboration:** Governments can encourage collaboration between healthcare, education, and community services to streamline resources and provide coordinated care for individuals with IDD. Policies promoting shared funding and joint training sessions could lead to better communication

		between sectors, reducing gaps in care and improving outcomes. **Increasing Funding for IDD Programs:** Governments can establish dedicated funding initiatives to expand services for individuals with IDD while enhancing existing programs. Providing grants or subsidies to organizations that specialize in IDD care and research, could lead to improved access to services and the development of innovative solutions tailored to the needs of this community.
3	**Lack of Trained Professionals:** A shortage of trained professionals in IDD care significantly limits the support available for individuals with these conditions.	**Training for Non-Professional Caregivers:** Governments can support non-professional caregivers by providing accessible, affordable training programs focused on IDD care. These programs could cover communication strategies, behavior management, and understanding IDD. Offering online courses and community workshops can help caregivers improve their skills and access support, especially in underserved areas. **Expanding Training and Education for Professionals:** Governments could partner with universities and professional associations to include IDD-related coursework and practical experience in the training of future healthcare providers, teachers, and social workers. This could help increase the number of trained professionals equipped to support individuals with IDD and ensure that they receive high-quality care from the start. **Incentivizing Specialization in IDD Care:** Governments could introduce financial incentives, such as scholarships, loan forgiveness programs, or higher pay for professionals who specialize in IDD care. These policies could encourage more individuals to pursue careers in this field, addressing the shortage of trained professionals.

		Creating Certification Programs for Existing Professionals: Governments could establish certification programs for healthcare providers, educators, and social workers to gain specialized knowledge in IDD care. These programs would be designed to fit into professionals' current jobs, offering flexible online courses or workshops. This initiative would help professionals improve their skills, increase their earning potential, and expand their ability to support individuals with IDD. As a result, more professionals would be trained to provide high-quality, specialized care to people with IDD. **Increasing Collaboration with IDD Organizations:** Governments can foster partnerships between academic institutions, professional organizations, and IDD service providers to develop and implement specialized training programs. By collaborating with local and national IDD organizations, policies could ensure that training programs are directly aligned with the real-world needs of individuals with IDD. This would lead to more targeted and practical training, improving the quality of care and support available.

4	**Limited Resources and Funding for Individuals with IDD:** There is a significant gap in resources and funding for individuals with IDD, particularly for adults. Access to specialized programs, employment opportunities, and support services is limited, which makes it challenging for adults with IDD to live independently and fully engage in their communities.	**Addressing the Resource and Funding Gap in IDD Care:** Governments can increase investment in IDD-related services by allocating more financial resources to training programs, professional development, and research. They could also offer incentives, such as grants or tax benefits, to encourage professionals and paraprofessionals to enter the IDD care field and stay in it, long-term. Additionally, governments can create partnerships with educational institutions to offer specialized courses and certifications for IDD care professionals, as well as provide subsidies for organizations that offer IDD support services. **Integrating IDD Services into Existing Public Health and Social Service Systems:** Governments could also integrate IDD-specific support within established public health and social service programs. By training healthcare providers, social workers, and community service professionals to address the needs of individuals with IDD, these existing systems could offer screenings, referrals, and services alongside other public health initiatives. This could increase access to care and reduce the need for separate programs. **Adapting Education and Employment Programs for IDD:** Existing education and vocational training systems can be adapted to better serve individuals with IDD. By incorporating specialized career training, apprenticeships, and job placement support within current educational and workforce development programs, governments can help adults with IDD transition into meaningful employment. **Creating Flexible, Community-Based Support Programs:** Governments could develop community-based programs that offer tailored support to adults with IDD. These programs could focus on life skills, independent living, and employment training, using existing community resources such as local

		nonprofits, schools, and volunteer networks. By partnering with these organizations, governments could create cost-effective solutions that allow individuals with IDD to live more independently and participate in their communities. **Repurposing Existing Public Infrastructure for IDD Services:** Governments could repurpose existing public infrastructure, such as community centers, libraries, or senior care facilities, to provide IDD-specific programs. This could include offering employment readiness programs, social activities, and peer support groups. **Leveraging Technology for Support and Independence:** Governments can encourage the development of technology-driven solutions to help adults with IDD live more independently. This could include mobile apps, online platforms, or wearable devices designed to assist with daily living tasks such as managing schedules, medication reminders, or navigating public spaces. Virtual platforms could also offer job training programs, social interaction through online communities, and mental health support through teletherapy. These technology solutions can provide cost-effective access to services, especially in remote or underserved areas with access to the internet. In areas where technology may not be accessible, governments could include establishing local community centers where in-person services could be offered.

5	**Limited Involvement of Interested Parties in IDD Policy Development:** There is a significant gap in involving individuals with IDD, their families, and key interested parties in the development of IDD care models and policies. Non-profits, advocacy groups, local organizations, and other relevant parties are often underrepresented in shaping the policies and practices that directly impact the IDD community. By excluding these voices, policies may lack important insights and fail to address the real, lived experiences of those with IDD.	**Establishing Inclusive Policy Development Platforms for IDD:** Policymakers could create advisory boards or platforms that actively involve representatives from non-profits, advocacy groups, and community organizations, as well as individuals with Intellectual and Developmental Disabilities, their families, and caregivers. These platforms could bring together a diverse range of voices through regular consultations, ensuring that all interested parties have a direct role in shaping policy decisions. By facilitating structured discussions, feedback sessions, and collaborative workshops, these platforms could identify the unique needs and challenges of the IDD community, thus ensuring that policies are responsive and relevant. **Global Adaptation and Implementation:** To take this model internationally, policymakers could establish global networks of advisory platforms to encourage cross-border collaboration. By sharing best practices, research, and case studies from various countries, these global platforms could identify common challenges faced by the IDD community worldwide and help promote the adoption of inclusive, culturally sensitive policies. These networks would ensure that IDD care policies are flexible and adaptable to different regional contexts, accounting for local differences, cultural views, and specific community needs. **Fostering Psychological Safety:** These platforms could set clear ground rules to promote respect, active listening, and empathy, ensuring that all voices are heard and valued. Providing anonymous feedback channels and employing trained facilitators could help create a safe environment where individuals feel comfortable sharing their perspectives without fear of judgment or retaliation. This would encourage open dialogue, enabling better-informed policy decisions and fostering trust among interested parties.

Other Gaps in Guidelines Addressable Through Policy Initiatives		
1	**Lack of a Centralized Platform for Resources:** Without a centralized platform, not only caregivers but also policymakers face challenges in accessing and utilizing research findings, data, and evidence, which are essential for shaping policies, developing effective programs, and making informed decisions on resource allocation.	**Global Centralized Platform for IDD Care Resources:** Policymakers can support the development of a centralized platform by enacting policies that require government agencies or public health organizations to collaborate with experts in IDD care, technology developers, and non-profit organizations. They can allocate funds to build and maintain this platform and ensure its content is inclusive and regularly updated. Policymakers can also ensure that the platform is easily accessible to caregivers, healthcare providers, and educators by integrating it into existing healthcare and education systems, making it a trusted and reliable resource.
2	**Limited Affordability and Accessibility of IDD Care Resources:** Many IDD care resources and guidelines are published in journals or on websites that require expensive memberships or fees, making them unaffordable, particularly in low- and middle-income countries. This creates a barrier not only for caregivers but also for policymakers, limiting their ability to access critical information and stay informed about the available resources and best practices for IDD care.	**Enhancing Access to IDD Care Resources through Policy Initiatives:** Policymakers can create initiatives to make IDD care resources more accessible by partnering with global organizations and research institutions to provide free or low-cost access to essential guidelines and research. This could include developing open-access platforms, offering government-funded subscriptions for key resources, or collaborating with international health organizations to provide localized, cost-effective training and materials for IDD care.
3	**Limited Access to Community Resources:** Caregivers and practitioners face challenges in connecting individuals with IDD and their families to community-based resources, such as employment, recreational activities, and care services. This lack of access to resources limits their ability to offer comprehensive support and guidance.	**Community Resource Mapping and Development:** Policymakers should first map existing community resources for individuals with IDD, such as job programs, recreation opportunities, and mental health services. If existing services are inadequate or unavailable, new programs can be developed, such as vocational training, inclusive recreational facilities, or expanded mental health support. By working with local governments, non-profits, and private organizations, policymakers can fund and create these

	As a result, caregivers face increased stress and challenges in providing well-rounded care for individuals with IDD.	services to ensure families and caregivers have better access to the support they need.
4	**Challenges in Navigating Legal Systems:** Families often face difficulties in understanding and navigating complex legal processes to access essential services. This includes challenges in securing legal rights related to housing, employment, and healthcare for individuals with IDD, as well as understanding eligibility requirements for government assistance programs.	**Improve Navigation of Legal Systems for IDD Services:** Policymakers can simplify and streamline legal processes for families and organizations supporting individuals with IDD by creating clear, accessible resources that explain legal rights and eligibility requirements for housing, employment, healthcare, and government assistance programs. They can also work to make legal aid services more available and affordable, ensuring that families and organizations have the support they need to navigate complex legal systems. Additionally, policymakers could advocate for laws that promote better protection of the rights of individuals with IDD, making access to essential services more straightforward and less burdensome.
5	**Barriers to Accessing Funding for Services:** Both families and organizations serving individuals with IDD face challenges navigating complex and confusing funding processes. This difficulty in securing financial support for essential services, such as respite care, specialized education, and therapy, limits access to critical resources for individuals with IDD.	**Improve Access to Funding for IDD Services:** Policymakers can push for increased funding for IDD-related services and ensure that financial support is easily accessible through government programs. They can also create a centralized platform that allows families and organizations to quickly find and apply for available funding, reducing the complexity and delays associated with the current application process.
6	**Insufficient Integration of Interested Parties** There is a lack of integration and emphasis on the role of community interested parties, such as non-profits, advocacy groups, and local organizations, in shaping IDD care models and policies.	**Inclusive Policy Development Platforms:** Policymakers should create advisory boards or platforms that include representatives from non-profits, advocacy groups, and community organizations, as well as individuals with IDD, their families, and caregivers. By incorporating these diverse voices into the policymaking process, these platforms ensure that the needs and perspectives of all are reflected in national care policies for IDD care.

7	**Lack of Technological Innovation in IDD Caregiving:** There is a significant gap in the development of technology specifically designed for caregiving for individuals with IDD. Until innovative tools and solutions, such as assistive devices, virtual platforms, and telehealth options, are properly developed, caregivers and practitioners will have limited resources to enhance care and improve caregiving practices.	**Drive Technological Innovation in IDD Caregiving:** Policymakers can help by prioritizing and funding research and development of technology specifically tailored to the needs of individuals with IDD. This could include grants or incentives for tech companies to create assistive devices, telehealth solutions, and virtual platforms that enhance caregiving practices. Additionally, policymakers can facilitate[xli] collaborations between technology developers, healthcare providers, and caregiving organizations to ensure these tools are effective, accessible, and user-friendly.

DISCUSSION

The gaps identified in global clinical guidelines and resources for IDD represent critical challenges but also present significant opportunities to improve care systems for individuals with IDD worldwide. Among the most pressing issues are the scarcity of comprehensive frameworks and tools for IDD population compared to conditions like autism; absence of centralized platforms for care guidelines; infrequent updates to existing resources; low levels of awareness; the lack of culturally relevant and intersectional frameworks; and inadequate specialized training and support for caregivers. These issues affect the timely diagnosis, quality of care, and overall well-being of individuals with IDD, yet they also point to critical areas where targeted interventions can lead to meaningful improvements, benefiting both the pediatric population and older individuals, throughout their lifespan.

One of the most significant challenges in the care of individuals with IDD is the scarcity of comprehensive frameworks and tools specifically tailored to their needs. Unlike other conditions, IDD care lacks detailed guidelines, evidence-based practices, and specialized tools that healthcare providers and caregivers can rely on across the globe. This results in fragmented care and inconsistent interventions across different regions, healthcare systems, and practitioners, making it challenging for individuals with IDD to receive the consistent support necessary for success in critical areas such as education, employment, social integration, and healthcare access.

Additionally, caregivers often face difficulties in managing the complex needs of individuals with IDD, which can lead to burnout and inadequate care. The development of such frameworks, while complex, presents a valuable opportunity to provide actionable resources that will help improve care practices for individuals with IDD.

Another key concern is the absence of centralized, easily accessible platforms for IDD care guidelines. Caregivers and healthcare providers often struggle to access up-to-date, evidence-based practices, which leads to inconsistent interventions and fragmented care. Developing a centralized platform could ensure that accurate and standardized information is readily available, enabling caregivers and professionals to provide more effective and timely support. However, implementing such platforms requires addressing infrastructure limitations, and ensuring content remains updated and locally relevant. Despite these challenges, advances in technology and digital health platforms offer a promising pathway to bridge this gap efficiently.

The lack of awareness and persistent stigma surrounding IDD remains a significant barrier, particularly in low- and middle-income regions. This gap often leads to delayed diagnoses, social isolation, and discriminatory practices, which can severely impact the quality of life for individuals with IDD and their families. Addressing this issue requires culturally sensitive public awareness campaigns that educate communities about IDD and challenge harmful stereotypes. Educational programs in schools and community outreach initiatives that promote inclusivity and celebrate neurodiversity can be powerful tools to shift societal attitudes. Overcoming such biases can be challenging, but starting by normalizing IDD as a natural part of our human diversity could challenge stereotypes, reduce stigma, and pave the way for individuals with IDD to fully participate in their communities and lead fulfilling lives.

The current lack of intersectionality in IDD care guidelines further exacerbates disparities in care. Many existing frameworks are derived from research in high-income, Western settings and fail to consider the unique needs of diverse cultural and economic contexts. Developing adaptable, culturally sensitive guidelines through collaboration with regional experts, families, and interested parties can address this gap. While balancing global best practices with local adaptations is complex, fostering such partnerships ensures that care models are not only effective, but also equitable and inclusive across varied settings.

Equally critical is the limited involvement of individuals with IDD, their families and interested parties in the policymaking process. Care strategies that exclude their voices risk being misaligned with their actual needs and preferences. Creating mechanisms for meaningful participation, such as advisory boards and focus groups that are accessible to individuals with IDD, can help develop person-centered policies. While logistical and communication challenges exist, advances in inclusive communication tools and practices provide solutions that can make these processes more feasible and impactful.

Lastly, the lack of specialized training and support for caregivers, both professional and familial, remains a significant barrier to quality care. Caregivers often face burnout due to inadequate resources and preparation for addressing the unique challenges associated with IDD. Investing in comprehensive training programs, mentorship opportunities, and emotional support systems for caregivers can address this gap. While such initiatives require funding and systemic commitment, they are essential for building a resilient and skilled workforce equipped to provide high-quality care.

Hence, while each gap presents unique challenges, overcoming them will lead to a more equitable, inclusive, and effective care system. Through a combination of policy innovation, public awareness, and collaboration among all interested parties, these gaps can be addressed to improve the lives of individuals with IDD worldwide.

CONCLUSION

This paper provides a comprehensive examination of global clinical guidelines for the care of individuals with IDD, identifying key gaps and highlighting opportunities for improvement. Through an in-depth literature review, the paper explores core areas addressed by existing guidelines and uncovers significant shortcomings in meeting the diverse needs of individuals with IDD. Among the most pressing challenges are the absence of centralized platforms for care guidelines; infrequent updates to existing resources; pervasive stigma and limited awareness; the lack of culturally relevant and intersectional frameworks; insufficient specialized training and support for caregivers; and the scarcity of comprehensive frameworks and tools for IDD, compared to conditions like autism. This lack of resources and guidelines results in inconsistent care practices and creates barriers for caregivers and healthcare providers seeking clear, evidence-based approaches to support individuals with IDD effectively.

By analyzing these gaps, this paper underscores the importance of developing more inclusive, accessible, and person-centered care models. It highlights the need for comprehensive resources and training programs tailored specifically for IDD, ensuring consistent and effective care practices across diverse settings. Additionally, the paper emphasizes the need for guidelines that are adaptable to various healthcare environments, particularly in under-resourced regions, and that actively incorporate the voices and lived experiences of individuals with IDD, and their families. Collaborative efforts among healthcare providers, caregivers, and community networks are essential to bridge these gaps and build support systems that are equitable, effective, and culturally sensitive.

Beyond clinical care, the paper stresses the critical role of policy interventions in addressing systemic barriers faced by individuals with IDD. Policies aimed at raising awareness, reducing stigma, and increasing funding for IDD services are crucial to improving care and support systems. This paper also advocates for initiatives to ensure robust training for healthcare professionals, foster the inclusion of individuals with IDD and interested parties in policymaking processes, and expand access to resources for individuals with IDD, including employment opportunities and specialized support services.

Finally, this paper aims to drive a global shift toward better care for individuals with IDD by advocating for more comprehensive and adaptable clinical guidelines, as well as meaningful policy changes. These efforts are focused on creating a future where individuals with IDD receive the support, compassion, and effective care they need to lead fulfilling lives.

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Pankaj B. Shah, Associate Dean Research, Professor Community Medicine, SRMC & RI, SRIHER, Chennai, India. He completed his HOD tenure of more than 7 years. He is an MD, PhD in Community Medicine and completed the National Medical Commission Advance course in medical education and international FAIMER Fellowship at GSMC, Mumbai. He is part of various committees of NMC, ICMR, and Cochrane Systematic Review conferences. He has many international and national publications and awarded grants from WHO, ICMR, AIIMS Delhi, and SPARC Govt of India.

Janet Somlyay, DNP, CPNP-AC/PC, PMHS, PMHNP-BC, is a Nursing Lecturer faculty at Rider University, Department of Health Sciences and Nursing, Lawrenceville, NJ. She is board-certified as a pediatric nurse practitioner, pediatric mental health specialist, and psychiatric nurse practitioner. She has a Doctor of Nursing Practice in child family psychiatric mental health nurse practitioner from Arizona State University, post-Master's certificate from the University of Wyoming, Master´s of Science in perinatal nursing from the University of Utah, and a pediatric nurse practitioner degree from the US Air Force School of HealthCare Science in Texas.

Scott Spreat, EdD serves as the Vice President of Evaluation and Research at Woods System of Care, where he leads the Woods National Research and Evaluation Center. The Center is dedicated to promoting and conducting policy-related research, both independently and in collaboration with other research organizations. In addition to conducting research, the Center's mission is to inform decision-makers who influence policy and legislation impacting the individuals served by Woods System of Care. In recent years, Dr. Spreat has also served as the Research Director for the Center for Disability Information, where his research focused on workforce challenges within the intellectual disability sector. He was a member of the American Association on Intellectual and Developmental Disabilities (AAIDD) Terminology and Classification Task Force, contributing to the development of the definition of Intellectual Disability. Dr. Spreat holds a doctorate in Educational Psychology and is a licensed psychologist. He previously worked at Temple University's Woodhaven Center, where he conducted research, directed the clinical services department, and served as the Executive Director of the 284-bed program.

Nicholas Torres, MEd, has over 20 years of experience in executive management. Nicholas serves as the Executive Director of The Network: Towards Unity for Health (TUFH) an official non-state actor of WHO. He is also Co-Founder and CEO of Social Innovations Partners which publishes the *Social Innovations Journal*, manages the Social Innovations Institute & Lab, and incubates and launches high impact social sector models and enterprises. He teaches Nonprofit Leadership, Social Policy, and Social Entrepreneurship at the University of Pennsylvania. He serves on many regional boards including the Free Library of Philadelphia and Springboard Health National Advisory Board. Nicholas works at the cross-section between the private sector, government, and not-for-profits and aligns them toward collective social impact goals and public policy. He has led and founded multiple for-profit and not-for-profit social ventures that are driven both by social impact and financial sustainability measures. Some of his launched social ventures include charter schools, an early literacy technology platform; school-based health centers; and community-based satellite college sites.

Susan Waller is an experienced professional educator, researcher and curriculum designer. Susan has designed and facilitated courses and workshops across Australia and internationally on interprofessional education and clinical supervision. Susan led the regional nursing and allied health clinical education program for Monash University from 2014–2020 and from 2014–2017 managed and evaluated a large government funded simulation program in hospital and community health centers. From 2016–2020, Susan worked with colleagues at Monash University to facilitate and evaluate clinical supervision training across Victoria. Presently appointed as an Adjunct Senior Research Fellow, Susan continues to participate in a longitudinal multi-university graduate tracking outcome study. Susan supervised and examined theses on the Master of Surgical Education course at the University of Melbourne from 2017–2020. Susan completed the Harvard Macy courses on Health Professions Education (2007), on Leadership and Innovation in Education and on Assessment (2019). Susan's PhD, awarded by the University of Queensland in 2010, was in Interprofessional Clinical Education. In the past decade, Susan has contributed to 24 peer reviewed papers, four government reports and two book chapters. She has been a member of academic teams which have attracted just under 2 million dollars in grant support. Susan's clinical background is in paediatric physiotherapy. Graduating in 1981, Susan completed her Master´s of Paediatric Physiotherapy at the University of Queensland in 2003. Susan was the Senior Physiotherapist at a statewide disability service and supervised over 60 allied health professionals as a member of the Practice Support Team. Susan has been a member of the Human Research Ethics Committee of CPL since 2010. Dr Susan Waller is presently an Assistant Professor in the Department of Medical Education at the College of Medicine and Health Sciences at the UAE University, since January 2021. Susan coordinates the preclinical clinical skills courses and leads the college mentoring program. Susan's research interests are in interprofessional education and practice, workplace readiness, technology enhanced education and clinical supervision.

Minn N. Yoon, PhD, Associate Professor at the Mike Petryk School of Dentistry at the University of Alberta. One focus of her research is the care of vulnerable and marginalized populations exploring their healthcare experience through their voices and perspectives.

Anupriya Mishra, MBA, MS serves as the Manager at the Mollie Woods Hare Center for Excellence in Neurodivergence (Intellectual Disability, Autism, and Mental Health) at Woods System of Care. Anupriya is a dedicated nonprofit professional with a strong commitment to improving healthcare access and the quality of care for individuals with intellectual disabilities, autism, and mental health conditions. She holds a Master´s of Science in Nonprofit Leadership from the University of Pennsylvania and an MBA from ICFAI University, India, along with additional coursework in Psychology and Sociology from Harvard University. With expertise in donor relationships, fundraising, project management, research and writing, Anupriya has made significant contributions to underserved communities in both urban and remote rural areas of India. Anupriya’s passion for creating positive social change drives her ongoing work to expand economic opportunities, reduce migration pressures, and support communities globally.

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ADDITIONAL RESOURCES

- Intellectual and Developmental Disabilities (IDDs): https://www.nichd.nih.gov/health/topics/idds/conditioninfo
- Intellectual Disability: https://www.ncbi.nlm.nih.gov/books/NBK547654/
- The present, past and future of the study of intellectual disability: Challenges in developing countries: https://www.researchgate.net/publication/5381908_The_present_past_and_future_of_the_study_of_intellectual_disability_Challenges_in_developing_countries