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Describing healthcare systems for people with intellectual and developmental disabilities: Global chances and challenges

KEYWORDS: health systems, healthcare, intellectual disability, international, policy, practice

This Special Edition was conducted under the auspices of the *Health Issues* and *Comparative Policy and Practice* Special Interest Research Groups (SIRGs) of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). The aim of this Special Edition is to profile how the health systems in different global jurisdictions respond, if at all, to the health needs of people with intellectual and developmental disabilities. The rationale for the Special Edition is the dearth of information on health systems for people with intellectual and developmental disabilities, a noticeable omission given the substantial evidence of health inequalities experienced by this population. In 2006, Professor Gloria Krahn et al. (2006) coined the term “cascade of disparity” to describe these inequalities, which were evidenced at all levels of healthcare, from health promotion through to health outcomes. These inequalities occurred despite the protections of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which to date has been signed by 164 countries worldwide (United Nations, 2006). Article 25 of UNCRPD specifically protects the right of persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Most recently, health inequalities were starkly illustrated during the COVID-19 pandemic when people with intellectual and developmental disabilities experienced higher mortality and morbidity as well as discriminatory practices in treatment access (Cuyper et al., 2023; Jeste et al., 2020; Koks-Leensen et al., 2023; Maulana et al., 2021; Rosencrans et al., 2021; Tenenbaum et al., 2021). These COVID-19 experiences were the impetus for this Special Edition. The country profiles presented here address a key gap in the existing knowledge of how different countries address the healthcare needs

of people with intellectual and developmental disabilities and provide an opportunity to share good practices that may be adopted elsewhere.

Given that this Special Edition does not seek conventional research papers, but rather an overview of the structure of health systems, authors were guided from the outset on the type of submission required. As a first step, a pre-submission process was implemented to garner expressions of interest from prospective authors. In the case of multiple pre-submissions from one country, the editorial team facilitated collaborative development of a joint paper.

To encapsulate the pivotal elements deemed necessary by the editorial team, a distinct template was employed, contrasting the conventional structure of scientific papers. The template included the following sections: (1) Abstract; (2) Introduction to the general healthcare system within the participating country; (3) The organization of healthcare for people with intellectual and developmental disabilities; (4) Recent publications from the participating country, both popular or scientific that may be helpful for international readers to understand the national focus of research; and (5) A discussion reflecting on best practices and key challenges. This template aimed to promote similarity across submissions from different jurisdictions. Throughout the process of manuscript preparation, authors were invited to attend a number of Zoom meetings, which provided not only an opportunity to seek guidance and support on their work, but more broadly established an international network of researchers with an interest in this area. This network was an unintended yet welcomed consequence of the Special Edition.

The deviation from the conventional structure of research papers prompted an adaptation of the review

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process where every country profile was peer-reviewed by at least two local/national reviewers with expertise on the policies and delivery of healthcare (for people with intellectual and developmental disabilities) within the specific country. These reviewers were specifically tasked with checking if the provided national information was accurate and comprehensive in scope. In addition to these local/national reviewers, an editorial peer-review was performed to assure overall quality, adherence to the template, and clarity of the content for international readers.

This Special Edition describing global healthcare systems for people with intellectual and developmental disabilities brings together 13 country profiles. These papers describe how, if at all, these healthcare systems have developed to respond to the healthcare needs of people with intellectual and developmental disabilities. The profiles highlight not only the challenges faced by this population in accessing healthcare across 13 different countries, but also describe where national practices have been developed to specifically ameliorate disparities in healthcare specifically for people with intellectual and developmental disabilities. A qualitative synthesis process was conducted to provide a collective overview of these papers, which aimed to obtain a deeper understanding of underlying trends in healthcare for people with intellectual and developmental disabilities across countries. This synthesis is presented at the end of this Special Edition.

Notwithstanding the benefits of taking a global perspective on issues of relevance for people with intellectual and developmental disabilities, this Special Edition, via a series of online meetings, opened a global conversation among interested parties, which offered the opportunity for participants to learn from models of healthcare in other jurisdictions and consider shared learned lessons and key challenges. As editors, we hope that this exchange among a global network of researchers may develop into an accelerator of research for this vulnerable and disadvantaged population.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

ETHICAL STATEMENT

Not applicable.

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ORIGINAL ARTICLE



Synthesis: International perspectives on healthcare for people with intellectual and developmental disabilities

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Abstract

Background: The organization of healthcare for people with intellectual and developmental disabilities (IDD) varies across countries. Each country has developed unique practices embedded in their historical and organizational context. Understanding and sharing these practices across borders facilitates mutual understanding about healthcare needs of people with IDD and facilitates the adoption of effective strategies in other countries.

Aim: To provide a synthesis across the country-specific papers in the JPPID special edition and thereby identify underlying trends, challenges, and best practices in healthcare for people with IDD.

Methods: The papers in this special edition, which describe the organization of healthcare for people with IDD in 13 countries, were qualitatively analyzed using thematic content analysis, focusing on general characteristics, history, and context, organization of healthcare for people with IDD, challenges, and best practices.

Results: Each paper described a specific national history of evolution of healthcare for people with IDD, but our analysis showed that countries face similar challenges in healthcare for people with IDD. These challenges cover (1) access to healthcare, (2) quality of healthcare, (3) implementation, and (4) visibility of people with IDD. Consequently, people with IDD continue to face significant health disparities. Several best practices have been developed, ranging from making mainstream healthcare more accessible and suitable to providing specialized services, and advocating and raising awareness.

Conclusions: This synthesis is the first paper to include perspectives on healthcare for people with IDD across 13 countries. We identified that, despite differences in context, countries face similar challenges in improving healthcare for people with IDD. International collaboration and networking can provide essential tools in reducing health disparities that people with IDD face,

Abbreviations: IDD, Intellectual and developmental disabilities; ID, Intellectual disabilities; IASSIDD, International association of intellectual and developmental disabilities; SIRGS, Special interest research groups; UNCRPD, United Nations convention on the rights of persons with disabilities.

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starting with the challenges identified in this synthesis. This will require effort to especially include low- and middle-income countries.

KEYWORDS

health systems, healthcare, intellectual disability, international, policy, practice

1 | INTRODUCTION

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) underscores the fundamental principle that individuals with disabilities should have access to the same range, quality, and standard of healthcare as others (United Nations, 2006). Even though 187 countries or states have ratified this Convention (United Nations, n.d.), healthcare disparities for people with intellectual and developmental disabilities (IDD) in comparison to the general population exist, resulting in higher rates of avoidable deaths in people with IDD (Glover et al., 2017; Heslop et al., 2014). The COVID-19 pandemic has shed a light on these disparities by revealing disproportionate COVID-19 disease burden and mortality disparities among people with IDD compared to the general population (Cuyper et al., 2023; Koks-Leensen et al., 2023) and differences in access to healthcare during the COVID-19 pandemic (Maulana et al., 2021; Rosencrans et al., 2021).

The organization of healthcare for people with IDD differs internationally and each country has developed unique practices to give shape to this healthcare (Balogh et al., 2016; Ervin et al., 2014). Understanding how healthcare is organized across countries allows for collaboration and knowledge exchange between healthcare professionals, researchers, and policymakers at an international level, facilitating the development of improved healthcare systems worldwide (Raza, 2005). Additionally, this understanding is crucial for collaborative advocacy efforts and raising awareness about the needs of people with IDD and provides possible opportunities for joint research projects, shared resources, and cross-country initiatives (Freshwater et al., 2006). The different international responses to the COVID-19 pandemic for people with IDD highlight that understanding the context in which healthcare is provided is important to learn from other countries and improve the healthcare (Bump et al., 2021; Taggart et al., 2022). Despite the benefits of a shared understanding, there is currently limited information on international healthcare arrangements for people with IDD.

A global special edition was initiated under the auspices of the Health Issues and Comparative Policy and Practice Special Interest Research Groups (SIRGs) of the International Association of Intellectual and

Developmental Disabilities (IASSIDD). Contributors were invited to provide insight into healthcare services for people with IDD in different countries using the following template: national healthcare system, organization, and history of healthcare for people with IDD, recent publications, best practices, and key challenges. Submissions received on behalf of 13 countries are presented in this Special Edition. To obtain a deeper understanding of the underlying trends in healthcare for people with IDD across 13 countries, the current paper synthesizes the 13 special edition papers. This synthesis does not aim to evaluate country profiles, rather it explores international similarities and differences in the organization of healthcare for people with IDD, including the challenges and best practices.

2 | METHODS

The special edition on the international organization of healthcare for people with IDD was produced in 2023 and final publication was scheduled for 2024. The 13 papers were guided by a template predetermined by the editors, requesting a description of the national healthcare system, the organization and history of healthcare for people with IDD, recent publications on IDD healthcare, and a reflection on best practices and key challenges regarding healthcare for people with IDD. Throughout manuscript preparation, authors were invited to two Q&A Zoom meetings to ensure they understood the template and had an opportunity to discuss issues such as definitions of healthcare and IDD.

All 13 papers were qualitatively analyzed using thematic content analysis (Anderson, 2007). A combination of top-down and bottom-up approaches, based on the template and open coding of the manuscripts, was used to create a coding scheme, supported by ATLAS.ti software version 23.1.1. This coding scheme was applied to all 13 papers and the codes were grouped into five themes. All data on the five themes were extracted from the included papers. The analysis phases are described in Table 1. To obtain more insight into the themes, sub-themes were identified for the qualitative information provided in the papers (Table 2).

TABLE 1 Analysis phases.

Phase	Action	Result
1. Creating a coding scheme	Coding 8 submitted manuscripts using a combination of a top-down and bottom-up approach, discussing codes and discrepancies to reach consensus (MB, JN) Testing the coding scheme on 2 accepted manuscripts (MB)	Draft coding scheme consisting of 23 codes
2. Applying coding scheme to all manuscripts	Applying the final coding scheme to all 13 manuscripts (MB). Discussing cases of doubt (MB, JN, TP, CL)	23 codes applied to 13 accepted manuscripts
3. Grouping codes into themes	Grouping and reorganizing codes into categories and overarching themes and sub-themes through iterative discussion (MB, JN, TP, CL, GL)	5 themes with related subthemes and codes

3 | RESULTS

The five themes that resulted from the analysis will be elaborated on in this section: (1) General characteristics, (2) History and context, (3) Organization of healthcare, (4) Challenges, and (5) Best practices.

3.1 | General characteristics

The papers showed different interpretations of the term IDD. In some cases, the term IDD is understood to refer to individuals with intellectual disabilities (ID) who have additional developmental disabilities, while in other cases the term is understood to collectively refer to individuals with ID and individuals with other developmental disabilities who do not have ID, for example, autism. The growing use of the term IDD in the absence of an agreed definition can cause difficulties for estimating prevalence. For example, prevalence numbers of people with ID were estimated between 0.1% and 1.8%, while prevalence numbers of people with IDD ranged from 0.4% to 2.3% (Table 3). These numbers are based on estimations, registrations of public health and care services, national census or survey studies, or governmental sources resulting in

TABLE 2 Five themes, based on the template, with related subthemes and codes resulting from analysis.

Theme	Subthemes	Related codes
General characteristics	Prevalence Health disparities of three types: - Health problems - Access to medical care - Health outcomes Status of the UNCRPD Geographical differences	Statistics–prevalence Disparity Statistics–mortality UN convention Regional differences
History and context	Traditional, cultural, and religious beliefs Deinstitutionalization	History of IDD care Context of IDD care
Organization of healthcare	Key healthcare providers (Re)habilitation services Trained healthcare providers	Key healthcare providers Key differences with general population Education and training
Challenges	Access to healthcare Quality of healthcare Implementation Visibility of people with IDD	Accessibility COVID-19 Available expertise Training Demand exceeds capacity Implementation Responsibility for IDD healthcare Other
Best practices	Making mainstream healthcare more accessible and suitable Providing specialized IDD healthcare services Advocating and raising awareness.	Best practices Provisions Advocacy Involvement of people with IDD

large differences in presented prevalence number. Challenges in determining accurate prevalence figures were mentioned frequently and include IDD being unrecognized, incompletely registered, or registered under broader diagnostic categories such as “disability.” Furthermore, the papers mentioned that heterogeneity in included age groups and case definitions leads to differences in who is counted, resulting in a wide range of prevalence numbers

TABLE 3 General characteristics: prevalence of people with IDD.

Country	Prevalence numbers mentioned in special edition papers	Source of prevalence data
Spain	0.6%–1.0% ^a	Estimation Registrations of public health and care services
Norway	0.4%	Registrations of public health and care services
Australia	1.8% ^a	Estimation
England	0.5% ^a	Registrations of public health and care services
India	0.1% ^a	National census study
Sweden	Unknown	-
Ireland	1.4%	National census study
Poland	0.3% ^a	Governmental sources
Brazil	1.2% ^a	National health survey
Zambia	0.1% ^a	Estimation
Italy	Unknown	-
The Netherlands	1.5% ^a	Estimation
USA	2.3%	Extrapolation of smaller scale studies

^aConcerns ID (not IDD).

within and across countries. In addition, there is unclarity about the terms ID and IDD. These can be used interchangeably or as part of an even broader category “disability,” which creates unclarity and uncertainty regarding prevalence numbers of people with IDD.

All papers state that people with IDD experience health disparities, which were categorized into three types: (1) the prevalence and complexity of health problems, (2) access to and delivery of medical care, and (3) poor health outcomes such as life expectancy and avoidable deaths. To protect the rights of people with IDD, all papers reported that their country had either signed and/or ratified the UNCRPD. Papers describe that the ratification of the UNCRPD has impacted policy development concerning people with disabilities and led

to increased interest in the needs and rights of people with disabilities. Despite policy advances, recent evaluations of how disability health services are aligning with the UNCRPD noted that significant deficits in practice remain despite the introduction of the Convention, for example in poor access to mainstream health services.

Geographical differences in healthcare provision for people with IDD not only exist between countries but also within countries, for example between regions and jurisdictions. These differences can have a profound impact on the quality of healthcare that people with IDD receive. In some regions, well-established and specialized healthcare facilities provide services tailored to the needs of people with IDD, while in other regions resources might be limited and access to specialized healthcare for people with IDD could be challenging. Causes for these geographical differences can be found on both the national and local levels. At national level, resources can be unevenly distributed across regions causing problems in access due to long travel distances to access specialized services. At the local level, autonomous local authorities can be responsible for prioritizing, organizing, and financing healthcare provision within their geographical jurisdiction, leading to local differences in the availability of specialized staff, the amount of support provided, and the groups that are served.

3.2 | History and context

The way healthcare for people with IDD developed over time differs across countries. Each special edition paper describes its own national history of healthcare for people with IDD, reflecting changes in societal perspectives and social awareness. The diversity in histories across countries can be attributed to traditional, cultural, and religious beliefs and other developments that have further shaped their healthcare organization, including deinstitutionalization.

Religious, cultural, and/or traditional beliefs were reported to have greatly influenced and sometimes still influence healthcare for people with IDD in either positive or negative ways. Negative influences include discrimination, stigmatization, and false expectations to be able to cure IDD. Positive influences, for instance, include the provision of emotional, social, and economic support based in charities that originate from church activities. In addition, religion can be helpful for people with IDD and others in creating an inclusive community environment by embracing equality and making them feel accepted.

The papers reported that deinstitutionalization had a profound influence on the organization of healthcare for people with IDD. Achieving optimal community living

TABLE 4 Four main types of challenges in healthcare for people with IDD, identified in the papers.

Subtheme	Description
Access to healthcare	Healthcare services are less accessible for people with IDD due to geographical and transportation, financial, attitudinal, and organizational barriers
Quality of healthcare	The quality of healthcare services for people with IDD may be suboptimal because of a lack of competence and negative attitudes of healthcare professionals, and a lack of education or training for healthcare professionals
Implementation	Challenges of implementation include (1) limited professional resources (specialized equipment, services, and personnel) and financial resources to reinforce actions, (2) lack of coordination across services, cross-sectional capacity building, and immature interdisciplinary models of practice, and (3) no distinct services for individuals with IDD separate from those within the broader disability population
Visibility of people with IDD	The lack of data on the IDD population makes it more difficult to understand and respond to the health needs of people with IDD and is related to two challenges: (1) the identification of people with IDD, and (2) the linkage of data systems

with appropriate support continues to be an ongoing process. Irrespective, authors agree that deinstitutionalization has been a pivotal force in transforming the organization of healthcare for people with IDD toward greater inclusion and quality of healthcare.

3.3 | Organization of healthcare for people with IDD

The organization of healthcare for people with IDD is often described in local/national resources that are written in the language of that country and, although these references are included in the special edition papers, they may not be accessible to an international readership. According to the papers, people with IDD mostly start with using the same healthcare as the general population. However, an interdisciplinary approach is often needed. A wide variety of health professionals were cited as being involved in providing healthcare for adults with IDD including GPs, behavioral specialists (e.g., pedagogues, psychologists), ID physicians, medical specialists, (assistant) nurses, learning disability nurses, nurse practitioners, support workers, specialized therapists, nutritionists, occupational therapists, physiotherapists, and speech and language therapists. Specialized IDD expertise was found in multiple disciplines and included learning disability nurses, ID physicians, and specialist ID health teams.

Healthcare was reported to be organized differently for people with IDD who live in residential facilities, or participate in daily activity or (re)habilitation services as these services may also provide health and/or medical services. (Re)habilitation services may provide medical services along with healthcare services and can cover health assessments, treatment, medical check-ups, and health training for people with IDD. (Re)habilitation services were cited as being delivered by

interdisciplinary staff, which can include medical doctors and specialists, psychologists, physiotherapists, occupational therapists, nutritionists, speech therapists, social workers, and (disability) nurses.

3.4 | Challenges in healthcare for people with IDD

Challenges raised in the special issue papers were grouped into four subthemes as described in Table 4.

3.4.1 | Access to healthcare

People with IDD have lower levels of access to healthcare services compared to the general population. A variety of reasons for this were described including geographical and transportation barriers, financial barriers, attitudinal barriers, and organizational barriers.

Geographical barriers can affect the ability of people with IDD to receive healthcare, especially for those living in regional, rural, and remote areas because specialized services are usually located in urban areas. Transport to these services may be costly or unavailable. Financial barriers encompass people not being able to pay for healthcare services they need due to poverty. Negative and stigmatizing attitudes at the community and national level are also mentioned to hamper access to healthcare services because of unequal provision of opportunities and feelings of fear and shame in people with IDD and their families. Lastly, organizational barriers relate to services being only available to certain client groups, service provision not being systematic, and demand exceeding capacity.

The COVID-19 pandemic exacerbated the challenges experienced by people with IDD in accessing both primary and specialized healthcare. Poor linkages between disability and health services and an unpreparedness to respond

in a way that considers and supports the needs of people with IDD were revealed. The pandemic also showed that health and social services were largely unprepared to respond to the pandemic in an inclusive manner, for example, health messaging did not consider how people with IDD receive and understand information.

3.4.2 | Quality of healthcare

The quality of healthcare services for people with IDD was described as suboptimal by all papers. Healthcare professionals were described as often lacking the required competence to provide healthcare to people with IDD, leading to inadequate quality of healthcare for this population. Communication barriers, lack of knowledge about specific (especially rare genetic) disorders, negative attitudes, and lack of confidence in providing care to this population among healthcare professionals were deemed to lead to underdiagnosis and/or overtreatment.

Available education for future healthcare professionals does not cover the health needs of people with IDD according to the papers. There is a lack of training possibilities for current healthcare professionals to improve their skills and confidence when working with people with IDD. Especially for medical specialties that often encounter people with IDD, such as psychiatrists, general practitioners, and rehabilitation professionals, availability of training on the health of people with IDD is important. Appointing developmental medicine or IDD medicine as a specialized study was also mentioned as a solution to lower the health inequalities experienced by people with IDD.

3.4.3 | Implementation

Governments of all countries included in this special edition show a willingness to take action regarding healthcare policy (and support) for people with IDD. However, the implementation of these policies into action remains suboptimal leading to inadequate quality of healthcare for people with IDD. Suggested challenges of implementation include limited professional resources (specialized equipment, services, and personnel) and financial resources to reinforce actions. In addition, papers reported a lack of coordination across services, cross-sectional capacity building, and immature interdisciplinary models of practice. Furthermore, a commonly reported challenge was that specialized healthcare schemes, policies, and provision often address people with disabilities in general, while people with IDD have specific needs. Consequently, the needs of people with IDD were not deemed to be appropriately recognized.

3.4.4 | Visibility of people with IDD

There is a lack of data on the IDD population which makes it more difficult to understand and respond to the health needs of people with IDD. This is related to two challenges: (1) identification of people with IDD, and (2) linkage of data systems. First, the papers described a lack of sources that provided comprehensive and updated information about the number and characteristics of people with IDD and their healthcare service use. One reason mentioned for this is the inability to accurately identify people with IDD in available data, because of different definitions of IDD used, different data collection methods, and suboptimal registration of IDD in healthcare services. Second, a lack of interface between health and disability record systems can hamper health information exchange. This can be a problem for people with IDD who need coordinated healthcare provisions from different parts of the healthcare system.

3.5 | Best practices in healthcare for people with IDD

Various successful approaches to improve the accessibility of healthcare for people with IDD have been described in the special edition papers: (1) making mainstream healthcare more accessible and suitable, (2) providing specialized IDD healthcare services, and (3) advocating and raising awareness.

First, mainstream healthcare is made more suitable for people with IDD by training healthcare professionals and building their capacity to provide adequate care for people with IDD. *Training programs* identified ranged from individual advocates and organizations across the different health and disability professional groups equipping the sector in IDD health, to mandatory training programs that ensure that adults with IDD are prescribed medication appropriately. Furthermore, implementing *priority measures* such as cards that grant priority care to people with IDD, discounts for medications, allowing a companion to medical appointments, and other health and medical benefits were deemed by authors as making mainstream healthcare more accessible for people with IDD. These adjustments are often not organized specifically for people with IDD but for people with disability in general.

Second, *specialized healthcare services* for people with IDD are provided in a range of different forms. They can be situated in primary care or are accessible only on referral by primary or social services. Some services are available free of charge, while some are located in the private sector where access is hampered due to financial

costs and their location. Specialized healthcare services for people with IDD are often provided in multidisciplinary teams. Age and level of disability are mentioned as eligibility criteria for access to these services. Despite the existence of specialized IDD healthcare services, these are often only available on a small scale.

Third, individuals and governmental and non-governmental organizations have *raised awareness* about the rights of people with IDD and inclusion in society. They advocated for systemic change to the way healthcare is delivered for people with IDD. A key feature of this advocacy has been the involvement of people with IDD and their support networks in raising awareness about the challenges they face in accessing healthcare services.

4 | DISCUSSION

This synthesis explores underlying trends in healthcare for people with IDD across 13 different countries. Despite differences in historical developments and differences in current organization of healthcare for people with IDD, similar challenges are faced covering four subthemes: (1) access to healthcare, (2) quality of healthcare, (3) implementation, and (4) visibility of people with IDD. Although governments show willingness to take action regarding healthcare policy for people with IDD, they deemed the implementation of policy into action as insufficient, leading to suboptimal quality of healthcare for people with IDD. Consequently, people with IDD continue to face significant health disparities across countries. Several best practices have been mentioned, ranging from making mainstream healthcare more accessible and suitable to providing specialized services, and advocating and raising awareness.

4.1 | Comparison with existing literature

The challenges highlighted in this synthesis mirror concerns raised in existing literature. This synthesis further emphasizes the relevance of these concerns as they are mentioned across borders, while previous studies often focus on one country.

First, the synthesis demonstrates four types of barriers to accessible healthcare for people with ID that are pressing across countries. These barriers have also been identified in literature. A literature review by Alborz et al. (2005) emphasized attitudinal and organizational barriers to healthcare access for people with IDD. A recent review by Hashemi et al. (2022) has underscored transportation, attitudinal, and financial barriers to healthcare access for

people with disabilities in low- and middle-income countries. Internationally, the need for more accessible healthcare for people with IDD was previously acknowledged by Breuer et al. (2022). This synthesis supports the need for more accessible healthcare for people with IDD as a universal goal.

Second, this synthesis indicates room for improvement regarding the training and education of healthcare professionals. Previous studies have consistently pointed out a lack of confidence of healthcare professionals concerning caring for people with IDD (Desroches, 2020; Krahn et al., 2006; Wilkinson et al., 2012). Furthermore, the need to better prepare medical students in providing healthcare for people with IDD has been acknowledged (Breuer et al., 2022; Pelleboer-Gunnink et al., 2017; Ryan & Scior, 2016). This synthesis reinforces the urgency of implementing education and training strategies to enhance healthcare quality for people with IDD and provides examples of best practice training initiatives.

Third, this synthesis highlights that even though governments around the world show a willingness to improve healthcare for people with IDD, implementation into practice remains challenging. Previous studies have underscored the lack of professional and financial resources as key barriers to successful implementation (Bayley et al., 2012; Sharek et al., 2007). This synthesis' findings further emphasize the importance of specifying the needs of people with IDD separately from other populations with disabilities when designing and implementing healthcare initiatives.

Lastly, this synthesis recognizes the need for improved data on people with IDD and their healthcare. Recent papers by Krahn et al. (2023) and Reed et al. (2020) also call for additional information about the prevalence and health of persons with IDD to guide decisions about policies and programs. This synthesis underlines that this data is important to raise awareness about people with IDD and their health to ensure that resources are directed toward improving their healthcare.

4.2 | Strengths and limitations

This synthesis is, to our knowledge, the first to explore the organization of healthcare for people with IDD, covering 13 different countries and six continents. However, findings should be interpreted in light of the following limitations. First, it is important to note that the papers reflect the understanding and prioritization of the authors with regard to the organization of healthcare in their country. To prevent bias, all papers were peer-reviewed by local reviewers as well as international



reviewers. In this way, the contextual accuracy was checked at least by two local experts.

Second, the template used for structuring the special edition papers was based on the cumulative experiences of the editorial team and insights the team gathered from international discussions at conferences and the IASSIDD Health Issues and Comparative Policy and Practice SIRGs. Because the members of the editorial team are from well-resourced countries, their perspectives and approaches may differ from those of researchers from less-resourced countries. While the editorial team intended to provide an inclusive template that was applicable to all participating countries, the template might have been not sensitive enough to capture the nuances of cultural differences and some authors may have experienced difficulties in using the template. As a consequence, when needed, adaptation of the template to national contexts was encouraged and two zoom meetings were organized to aid authors in the development of their papers.

Third, different interpretations of certain fundamental concepts (e.g., institution, IDD /ID, and medical care) among participating authors may have led to differences in descriptions between countries. The terms ID and IDD were used interchangeably across papers, making unclear what group is meant and for some countries the distinction was not clear to be made. While efforts were made to mitigate this limitation through discussing different interpretations with authors, the inherent complexity of these concepts remains a present limitation.

Lastly, the limit of 3000 words per article may have hampered authors to comprehensively elucidate the complex healthcare organization of people with IDD. However, the word limit stimulated condensed descriptions of essential aspects of healthcare for people with IDD. Nevertheless, it is important to recognize that this might have led to oversimplification of the complex nature of healthcare systems. Despite the limited word count, some papers provided information that was not prompted by the template. These additions seem to be considered by authors as valuable enough to warrant their inclusion, despite the constraints on word count.

4.3 | Implications for research and practice

The challenges highlighted in this synthesis can be considered universal challenges in the healthcare for people with IDD. It is important to collaborate across borders to face these challenges and facilitate the development of more inclusive healthcare systems worldwide. This will require effort to especially include low- and middle-

income countries (Emerson, 2021). Collaborative advocacy efforts and cross-country research projects can be facilitated by this synthesis, providing context to the international healthcare arrangements for people with IDD. The best practices identified in this synthesis offer valuable insights and ideas concerning the improvement of healthcare for people with IDD. However, successful translation of best practices into different contexts is not straightforward and necessitates careful consideration. Furthermore, research concerning the effects of innovative projects and best practices is desired.

5 | CONCLUSION

The 13 participating countries have their own distinct history and healthcare arrangements for people with IDD. This synthesis reveals that these countries face similar challenges in enhancing healthcare for this population. Collaborative efforts, combining expertise, resources, and experiences across borders, are crucial in translating policies into impactful actions that can address the inaccessibility, inadequacy, and implementation and data gaps to develop inclusive healthcare systems that meet the needs of people with IDD.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

ETHICS STATEMENT

This synthesis meets ethical guidelines and legal requirements.

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Healthcare for people with intellectual and developmental disabilities in Italy

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Abstract

The Italian healthcare system is public and freely available to the population. With a few exceptions, there are no distinctions between the healthcare services and practices (e.g., primary care) designed for the general population and those for individuals with intellectual and developmental disabilities (IDD). Prevalence data on adults with IDD are lacking and most disability policies and resources are designed for people with disabilities broadly defined, without specification based on disability type or severity level. Recent legislation provides specific supports for individuals with severe disabilities or autism spectrum disorder. This paper describes the legislation and health policies developed for people with disabilities, the organization of the Italian healthcare system, and the organization of disability support services and healthcare services. Strengths (e.g., availability of many financial resources, adoption of biopsychosocial approach to disability, presence of innovative projects to address the healthcare needs of people with IDD) and weaknesses (e.g., lack of distinction among disability types, territorial differences, lack of disability training of healthcare providers) of the current healthcare practices are reported and discussed.

KEYWORDS

health, ID, medical care, policy, system of supports

ITALIAN HEALTHCARE SYSTEM

Statistics on intellectual and developmental disabilities population

Specific terminology distinguishes between ID, developmental disability (DD), and intellectual and developmental disabilities (IDD). ID is defined as significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills that manifest during the developmental

period (APA, 2022; Schalock et al., 2021a). DD (a) is defined as a severe, chronic disability that is attributable to a mental or physical impairment or a combination of mental or physical impairment; (b) is manifested before 22 years old; (c) is likely to continue indefinitely; (d) results in functional limitations in three or more major life activity areas; and (e) reflects the individual's long term need for a combination and sequence of special, interdisciplinary, or generic services and individualized supports (Developmental Disabilities Assistance and Bill of Rights Act Amendments

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of 2000). The term IDD is used to refer to people with ID and/or DD (Schalock et al., 2021b).

The prevalence of ID is often found to be around 1% globally and varies widely (range: 0.05%–1.55%; Maulik et al., 2011; McKenzie et al., 2016), depending on study settings, methodologies, age groups, and case definitions (McKenzie et al., 2016). Among Italian school children, ID was the most common type of disability in elementary and middle school, impacting 42% of students receiving special education (National Institute of Statistics, 2020). Moreover, 51% of students with ID have multiple disabilities (National Institute of Statistics, 2020). The prevalence of autism spectrum disorder (ASD) among 7–9 year olds was found to be 1 in 87 in 2016 (Narzisi et al., 2020) and 1 in 77 in 2021 (Ministry of Health, 2021a) with a male to female ratio of 4.4.

Among Italian adults, however, neither ID nor DD prevalence research has been conducted. The only population-level disability estimate comes from the reports of the National Institute of Statistics, that includes only the so-called *Global Activity Limitations Indicator* as disability identifier: “Having limitations due to health issues, for at least six months, that limits daily living activities.” The National Institute of Statistics estimated that approximately 5% of Italian adults had a disability according to this definition (National Institute of Statistics, 2019). For this reason, in this paper, we will refer to individuals with disabilities, except where otherwise noted.

Characteristics, organization, and financing structures of the healthcare system

The Italian national healthcare system (“Servizio Sanitario Nazionale” [SSN]) was established with Law 833 (1978) and later implemented with Legislative Decree 502 (1992). It guarantees health as a fundamental right for all citizens (Italian Constitution, Article 32). SSN is public and based on three fundamental principles (Ministry of Health, 2019a): universality (health is a community resource and healthcare services are for the whole population), equality (all citizens must access to the SSN services regardless of individual, social, or financial differences), and equity (healthcare services must be high-quality, effective, adequate, and transparent for all).

Three basic types of assistance are guaranteed: collective prevention and public health, health and social programs, and hospital care (Ministry of Health, 2019b; Prime Minister Decree 65, 2017). The SSN is organized into two primary levels: central state level (i.e., Italy and its governmental institutions, like the Ministry of Health)

and regional. The Central State establishes goals and standards for each of the 20 Regions to achieve (Ministry of Health, 2019a). Regions are further divided into 110 Local Healthcare Units (“Azienda Sanitaria Locale” [ASL]), each of which covers a specific geographical area (e.g., Tuscany has three ASLs: Center, North-West, and South-East) (Ministry of Health, 2019a). In accordance with Law 833 (1978), which requires services be offered as close as possible to people's places of living, ASLs are further subdivided into districts to provide services in areas of limited dimensions (a surface area of 440 km² and a population of 85000 on average) through hospitals and health facilities.

The SSN is partially funded by the following sources: (a) a percentage of two taxes paid by the population (income tax and a tax on companies), (b) revenue of the ASL, (c) national budget (including the “National Health Fund”), (d) other minor sources. In addition, individual citizens pay a portion of healthcare costs (the so-called “ticket”), according to a sliding fee scale, for the following services: some medicines, specialist visits and exams, and non-urgent interventions performed in the Emergency Department to people over 14 years old. Italian citizens may be exempted from paying the “ticket” based on age (i.e., citizens under 6 and over 65 with an annual income not exceeding 36151.98€), family income, disability (Law 104, 1992) status (e.g., health impairments acquired during previous military service), presence of specific health conditions (e.g., pregnancy) or healthcare services performed (cancer or HIV screening). Although most healthcare facilities are public, a small number of private healthcare facilities also exist, most (93%) of which are accredited and paid by SSN (meaning that patients pay only the “ticket”).

Legislation and policy regarding people with disabilities

The Italian Constitution states that all citizens must have equal rights and be protected from discrimination. Law 104 (1992) codifies these principles concerning rights, social inclusion, and assistance of citizens with disabilities. Law 104 (1992) defines disability as “physical, mental or sensory impairment, stabilized or progressive, which causes difficulties in learning, relationships or work integration and is associated with social disadvantage or marginalization” (Law 104, 1992, art. 3). Disability certification is needed to access financial, education, and other resources. Law 104 (1992) covers various topics (e.g., prevention and early diagnosis, treatment and rehabilitation, school and work inclusion, guardianship). In terms of healthcare, Law 104 pursues the social and

functional recovery of individuals with disabilities and assures services and supports for preventing, treating, and rehabilitating impairments.

Additional supports were codified in Legislative Decree 502 (1992), Presidential Decree 87 (1994), and Law 162 (1998), which established Personalized Support Plans (“Piani Personalizzati di Sostegno”) for people with severe disabilities (see the section *Disability and Support Services, Organization and Resources* of this paper).

Legislative Decree 502 (1992) and Prime Minister Decree 65 (2017) direct the establishment of a preventative service department in each regional district to function as an institutional guarantor of health promotion, prevention of diseases and disabilities, and individual quality of life improvement through the provision of rehabilitation services.

Presidential Decree 87 (1994) provides for the healthcare needs of children with disabilities, specifically: (a) formulation of a functional diagnosis (i.e., description of functional impairments) by a multidisciplinary team that collects psycho-social and clinical information in cognitive, affective-relational, linguistic, sensory, motor, neuropsychological and autonomy areas (Presidential Decree 87, 1994) and that considers all the factors having a role for the development and manifestation of the disorder (Balboni & Cubelli, 2011); (b) formulation of a functional dynamic profile (e.g., describing the child's strengths and weaknesses and the potential development in the short and medium term); (c) individualized educational plan for the child with a disability (a document describing the interventions prepared for the child in a given period of time, in order to realize their right to education and training). These directions were explicitly extended later to individuals with ASD (Law 134, 2015), whose multidisciplinary healthcare team are required to receive education and clinical experience on ASD and neurodevelopmental disorders.

In March 2007, Italy signed the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) and, in May 2009, the Italian Parliament ratified the CRPD and the related Optional Protocol with Law 18 (2009), which also established the National Observatory on the Condition of People with Disabilities. In 2016, the National Observatory on ASD was also established (Ministry of Health & Italian National Institute of Health, 2016). These provisions develop programs for the promotion of the rights, health, social inclusion of individuals with disability and ASD, respectively, and to promote research to identify priority areas of actions and interventions relevant to the field.

Recently, several laws were passed, mainly concerning allocating financial resources to the healthcare services intended for people with disabilities (e.g., Council

of Ministers, 2021). With the Next Generation EU program, the European Union provided resources to each state member for the three-year term 2021–2023 to cover a variety of financial demands consequent to the COVID-19 pandemic. The Italian National Recovery and Resilience Plan (“Piano Nazionale di Ripresa e Resilienza”) is part of this program. The Plan allocates funding for six missions to foster the wellbeing of people with disabilities. For example, Mission 1 (“Digitalisation, innovation, competitiveness, culture and tourism”) concerned interventions to remove the architectural and sensory barriers in museums and libraries. Specifically regarding the healthcare of people with disabilities, Mission 5 (“Inclusion and cohesion”) provided investments in social infrastructures, community, home, social, and health services aimed to improve the independence of people with disabilities, while Mission 6 (“Health”) regarded the implementation of interventions to improve health assistance and services (e.g., the use of telemedicine) to promote truly universal access to public health (e.g., dismantling territorial differences in healthcare services and access) (Council of Ministers, 2021). In this sense, within Mission 6, the strengthening of home assistance and the upgrading of territorial structures and facilities are envisaged. For example, there is a project to create 1288 Community Houses (e.g., easily identifiable and accessible community care points with a “hub” that provides primary care, social, and welfare supports, with a multidisciplinary team of physicians, pediatricians, nurses, social workers, and other health professionals). The Community Houses were especially designed for those citizens with particular frailties, such as the elderly, people with disabilities, and people with chronic diseases and others with high support needs, to decrease the risk of their institutionalization and guarantee the needed healthcare services in a context that is independent and socially appropriate (Council of Ministers, 2021).

Law 227 (2021) updated existing legislation to be compliant with the guidelines of the CRPD (United Nations, 2006) and the Strategy for the Rights of Persons with Disabilities 2021–2030 (European Commission, 2021). In addition to updating disability laws and provisions, it revised its definition of disability to align with the International Classification of Functioning, Disability, and Health (World Health Organization, 2001) and the biopsychosocial approach. Moreover, this Law established the presence of a national disability guarantor for the protection and promotion of the rights of people with disability.

Finally, given the evidence about the importance of sport activities for the health of people with ID (Special Olympics, 2020) and to encourage the inclusion of individuals with ID through sport, Law 208 (2015) allocates

funds to the international program of sport training and competitions “Special Olympics Italy”. In addition to social inclusion, the Special Olympics program promotes the healthcare and self-care of athletes with ID, thanks to volunteer health professionals (nutritionists, podiatrists, ophthalmologists, dentists, audiologists) and medical students who offer athletes free screening of the highest quality.

THE ORGANIZATION OF HEALTHCARE FOR PEOPLE WITH DISABILITIES

Disability support services

Historical context

Deinstitutionalization in Italy began in 1978 with the Italian Mental Health Act (i.e., Basaglia Law or Law 180, 1978) that reformed the Italian psychiatric system. This Law required all Italian asylums (that hosted individuals with mental health and with disabilities, particularly ID) to close and be replaced with community-based care services. Recently, the Law “after us” (Law 112, 2016) reaffirmed that institutionalization must be avoided and provided assistance for people with severe disabilities to support their life course (e.g., support for services in one’s own home, programs to develop skills for managing daily life as independently as possible) in the absence of family support (e.g., after the death of their parents/guardians). Institutional care should be used only temporarily and only in emergencies (e.g., to access healthcare services that are not available with home-based care, or in case of a behavioral health crisis).

Organization and resources

Individuals with disabilities and their families receive some services from the public or institutional sectors (e.g., municipality, ASL, or cooperatives). However, the public resources are not enough to cover all the needs. Indeed, 49% of the families of people with disabilities do not receive any public support whatsoever. In addition, the number of resources available vary by territory (National Institute of Statistics, 2019). Thus, people with disabilities resort to private service support or informal support. In this framework following the dispositions of the SSN (Law 833, 1978) and Law 180 (1978), many social service companies provide social, health, educational services (Type A cooperatives), and job placement (Type B

cooperatives) to people with disabilities and other minorities (Montanari & Ruzzante, 2021).

Financial support is provided by the Italian government to people with disabilities and/or their families (Ministry for Disabilities, 2022). Parents of individuals with disabilities receive financial assistance lifelong (the so-called “assegno unico”) that differs based on several factors (e.g., income, number, and age of offspring). Single or unemployed parents may qualify for additional financial support (Ministry for Disabilities, 2022). Funds supporting healthcare include:

1. Fund for non-self-sufficiency (established with Law 296, 2006): aims to enhance care, services, and independent living for people with high levels of support needs and their caregivers.
2. Fund for assistance to persons with severe disabilities deprived of family support (established with Law 112, 2016): aims to avoid institutionalization and support people when leaving the family of origin. Interventions may support home care in family-type houses and co-housing settings similar to a family home, or interventions to support home-based care and to improve daily living skills and independence.
3. Fund for family caregivers (established with Law 205, 2017): provides financial support for non-professional care work performed by family caregivers.
4. Fund for the care of individuals with ASD (established with Law 208, 2015): aims to strengthen direct support staff by providing them with education and training on ASD, improve residential and semi-residential facilities, and enhance ASD research.

Law 162 (1998) provides funding to the Municipalities for Personalized Support Plans that provide social-welfare interventions for individuals with severe disabilities (e.g., personal and/or home assistance, educational assistance, day centers). The aim is to build on the person’s strengths to maximize independence, especially in managing daily activities and free time. These individualized interventions are designed by the families in conjunction with professionals, based on the person’s specific needs (e.g., physical therapy, daycare services, transportation, supported employment and housing, sport and social activities). Family members or guardians can request the Personalized Support Plan from their Municipality and, once determined eligible, they are redirected to specific associations (e.g., National Association of Families of People with Intellectual and/or Relational Disabilities) or cooperatives deputed to the provision of these services.

Italian municipalities allocate most of their financial resources to support the living arrangements of people with disabilities, including daycare and residential (or semi-residential) facilities, which are mostly used by individuals with higher support needs, followed by home-based care services, aimed to make adults with disability independent within their own home environment (Ministry of Health, 2019b; National Institute of Statistics, 2019). Residential facilities provide both social and healthcare services, and may be offered in community-based facilities. Although data on the use of independent living settings by people with ID is not reported, small community-based residential placements are less common and generally limited to individuals with mild or moderate ID without higher support needs (Academic Network of European Disability Experts, 2019).

Disability healthcare services

The Italian healthcare system provides the same services for people with and without disabilities. The SSN guarantees the inpatient, outpatient, and home-based care of all people with acute or chronic diseases according to the best practices and patient's needs (Prime Minister Decree 65, 2017). In Italy, healthcare services and social-support services are hardly distinguishable. As described, services provided to people with disabilities in their residential, semi-residential facilities, or home-based settings may include both healthcare services and support services. This happens because health, social services, and interventions (including rehabilitation and psychotherapy services) must be provided in an integrated manner (Law 328, 2000), enhancing the individual's abilities, minimizing the overall impairment, and involving family and community contexts (Prime Minister Decree 65, 2017).

In terms of primary care, citizens older than 14 years with or without disabilities are entitled to the following services, free of charge, from a family physician (Ministry of Health, 2021b): outpatient and home-based care visits for preventive, diagnostic, and therapeutic purposes, prescriptions for medicine and specialist services, requests of hospitalization, home-based care, some types of vaccinations, issuance of some medical certificates (e.g., excused absence from work/school). These same services are guaranteed for children by the pediatrician. Children are guaranteed pediatric services from birth to 6 years of age. For minors aged 6–14 years old, parents (or guardians) can choose whether to keep their pediatrician or switch to a family physician. Only minors with disabilities or certified chronic illness are allowed to stay

with their pediatrician until the age of 16. In addition, pediatricians provide preventive and screening examinations, checking for linguistic, socio-relational, psychomotor, and other developmental delays that may indicate the presence of IDD or ASD.

In addition to primary care, citizens with disabilities are entitled to specialized care, if needed, that can be public or private. The use and access to the Emergency Department services including the use of the universal telephone number “118” is available to people with and without disabilities (Ministry of Health, 2021b). For specialist visits in public services, the citizen must obtain a prescription from the family physician, schedule the service, and pay the “ticket,” unless exempt.

All individuals who need rehabilitation services must have an Individual Rehabilitation Plan. It is composed of one or more rehabilitation services to meet their individual needs, strengths, and weaknesses (Ministry of Health, 1998). The SSN guarantees the implementation of rehabilitation activities at outpatient clinics, home, hospital (ordinary hospitalization for people who require at least 24-h medical-nursing surveillance), accredited residential and semi-residential social-health facilities for people discharged from acute or rehabilitation hospitalization who need ongoing treatment to further recover their abilities but who no longer need medical care during the night hours (Ministry of Health, 2019c).

These residential and semi-residential social-health facilities offer intensive rehabilitation services (i.e., 3 h/day and 6 day/week interventions for no more than 45 days aimed at recovering important, complex, modifiable limitations) or extensive rehabilitation services (i.e., 1 h/day and 6 day/week interventions for no more than 45 days for patients with disabilities who have the potential to recover function and cannot benefit from intensive rehabilitation treatment). In both cases, the services are free of charge for patients. A third type of intervention in social-health residential and semi-residential social-health facilities is treatment to maintain the functional skills of people with higher support needs and stable physical, mental, and/or sensory disabilities. However, this latter type of treatment is only partially funded by the Health Service (Prime Minister Decree 65, 2017).

By law, healthcare services intended for Italians with disability should be provided by a multidisciplinary team of healthcare professionals who are experts and have had previous experience with the patient's condition (Law 104, 1992; Law 134, 2015; Prime Minister Decree 65, 2017). Yet, disability training programs are not required for health professionals, even among the continuing education programs that are required of all Italian health professionals. Disability training is only



available at the postgraduate level, always on a voluntary basis, and generally behind a paywall.

Furthermore, regarding healthcare facilities, today only a few offer a priority access to patients with disabilities needing outpatient services, adequate space in the Emergency Department, and specific rooms for the care of people with ID (Elisei et al., 2021; National Observatory on the Health in the Italian Regions and *Spes contra Spem*, 2016). However, some innovative projects have been implemented to address these needs and improve healthcare accessibility for people with ID and other disabilities (Elisei et al., 2021; Frondizi et al., 2021), including during the COVID-19 pandemic (Buono et al., 2021).

DISCUSSION

The Italian healthcare system is public and available to all Italian citizens, including individuals with disabilities for whom specific resources have been provided since the 1970s. Despite this extremely positive benefit, Italian healthcare services are generally not tailored to the particular needs of individuals with disabilities. Indeed, despite the availability of specific services for people with severe disabilities and higher support needs of individuals with ASD, disability is understood as a single condition, associated with limitations in daily living activities due to health issues that have persisted for at least 6 months. However, there are many types of disabilities, each of which has specific healthcare and support needs. Moreover, different types of disability may be associated with comorbidities, interacting in complex ways. For example, ID represents a heterogeneous group of etiologies, with a wide range of severity levels and comorbid physical and mental healthcare conditions. Consequently, people with different types of disabilities or with different levels of the same disability have different needs and require diverse types and levels of support. Furthermore, there are complex disabilities, such as rare neurodegenerative and neuromuscular pathologies, which also have specific needs currently not taken into consideration and specified in the legislation in force in Italy.

Making visible the invisible by knowing the prevalence of these disability subgroups represents the first step to understanding the ID population's health status, health determinants, and health needs, and accordingly developing adequate policies and practices to predict and meet these needs (Krahn, 2019). This is particularly relevant because there are large territorial differences in resource allocation and access. Many families of people with disabilities, especially those from Southern Italy, need to use private support services and healthcare services at their own expense (National Institute of Statistics, 2019).

Notwithstanding, promising changes that will lead to more equitable health are in progress, where the preferences of patients with disabilities are considered, valuing self-determination and independence (Law 227, 2021). Finally, disability is no longer viewed with a medical approach. The living context of the person with disability can be sources of health barriers or facilitators (World Health Organization, 2001).

Clearly stating that patients with disabilities must fully participate in all the decisions concerning their health (Law 227, 2021) implies that healthcare providers must be trained to properly care and interact with people with disability (and patients with ID specifically). Therefore, specific disability education should be introduced, standardized across the country, and required for all healthcare professionals, either as part of the degree programs or as mandatory courses in the continuing education programs (Bacherini et al., 2021, 2022). Research conducted in Italy echoes international findings that healthcare providers (including psychiatrists) for adults with disability (including ID and ASD) felt unable to meet the specific needs of these populations. Moreover, they are generally reluctant to care for these patients due to a severe lack of knowledge and training about neurodevelopmental disorders, but are generally willing to learn (Elisei et al., 2021; Italian National Institute of Health, 2021). A similar situation is observed in the field of oral healthcare for people with ID (Dellavia et al., 2009; Fernández Rojas et al., 2021).

In conclusion, to improve healthcare equity, access, quality of care provided to individuals with ID, and to decrease the healthcare disparities that this population face, the two most important future directions are: to develop a clear roadmap to collect better data on prevalence and health surveillance of people with ID at a national level, and establish education and training programs mandatory for all healthcare providers. Certainly, a prerequisite for these changes is the adoption of a clear definition of ID, distinguished either from IDD or DD (Havercamp et al., 2019; Schalock et al., 2021b).

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AB: Conceptualization; investigation; project administration; writing—original draft preparation; writing—review and editing. **IP:** Investigation; writing—original draft preparation; writing—review and editing. **GB:** Funding acquisition; supervision; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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SPECIAL ISSUE ARTICLE



Healthcare provision for Swedish persons with intellectual and developmental disabilities

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Abstract

This paper aims to give a short description of Swedish healthcare provision for persons with intellectual and developmental disabilities (IDD). Swedish persons with IDD should have access to the general healthcare system on the same terms as the general population, and thereby enjoy equal opportunities for healthcare of good quality. Reports from government agencies and interest groups, however, describe a decentralised and fragmented healthcare system that requires significant coordination; a lack of adjustments; a lack of specialised healthcare professionals; and gaps in healthcare provision. Research in recent years has reported unequal access to planned healthcare; excess mortality and premature deaths; and insufficient or inadequate support in end-of-life care. We conclude that health inequalities and healthcare challenges faced by Swedish persons with IDD might be caused by obstacles at several structural levels. Allowing persons with IDD to access timely and adequate healthcare requires the development of better opportunities for coordination of healthcare and social services, as well as training for healthcare professionals and direct support staff.

KEYWORDS

healthcare, inequalities, intellectual disability, policy

INTRODUCTION TO GENERAL THE HEALTHCARE SYSTEM OF SWEDEN

This paper is part of a special issue with the aim to provide an overview of healthcare provision for persons

with intellectual and developmental disabilities (IDD) in different countries. It presents a general introduction to the Swedish healthcare system and details those provisions specially available for persons with IDD. The paper has a focus on the adult population, but mentions, when relevant, healthcare for children with IDD.

Abbreviations: NBHW, National Board of Health and Welfare; SAHCSA, Swedish Agency for Health and Care Services Analysis; SFS, Swedish Code of Statutes; SOU, Official Reports of the Swedish Government.

The authors have written this paper jointly.

International perspectives on healthcare for persons with intellectual and developmental disabilities.

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Population and available statistics

Sweden has a population of approximately 10.5 million people (Statistics Sweden, 2022). While statistics for the general population are readily available, the number of

persons with IDD can only be identified through administrative systems, e.g., statistics covering schools and social services. National and local registers covering patient data also contain some information on IDD. That is, population data for children and adults with IDD are available through services they access, or adjustments within these services. Available data therefore do not cover all persons with IDD living in Sweden. Furthermore, due to the Swedish legislation, persons with IDD cannot be differentiated from persons with autism (with/without IDD) in statistics on social services.

Swedish persons with IDD are entitled to apply for services according to the Act Concerning Support and Service for Persons with Certain Functional Impairments (SFS, 1993:387, henceforth the Swedish abbreviation LSS will be used). These services include, e.g., group homes, daily activity services, short time respite care, companion and escort services. According to the annual report of the National Board of Health and Welfare (NBHW, 2023a), 15 835 children and young adults under the age of 20 and 54 214 adults with IDD and/or autism accessed LSS services in 2022. While persons with IDD are also supported through the Social Services Act (SFS, 2001:453), no statistics are available based on diagnosis.

Persons with disabilities can apply for personal assistance through the Social Security Code (SFS, 2010:110). In December 2021, 6641 persons with IDD and/or autism were supported by a personal assistant (Social Security Agency, 2022).

Pupils with IDD generally attend schools with an adjusted curriculum. During the school year of 2021/22 the number of pupils with IDD in elementary school were 14 449, approximately 1.3% of all pupils, and 6754, almost 2%, in upper secondary school (Swedish National Agency for Education, 2022). This comprises pupils from the age of seven to approximately twenty.

ORGANISATION OF HEALTHCARE

This outline of the Swedish healthcare system is mainly based on relevant legislation and the webpages of government agencies and regional councils (regions). Swedish healthcare is highly decentralised (NBHW, 2019), and fragmented (Swedish Agency for Health and Care Services Analysis, 2016, henceforth SAHCSA) and political and financial responsibilities are dispersed across the government and several government agencies, regions, and municipalities. The description of the healthcare system covers somatic and psychiatric care. Persons with IDD access healthcare on the same terms as the general population, with some additional provisions: municipal primary healthcare and habilitation.

TABLE 1 Structure of the Swedish healthcare system.

Level	Responsibilities
Government	Legislation & principles Political guidelines Strategic funding, grants and occasional funding
Government agencies (a selection)	
National Board of Health and Welfare	Binding regulations and advisory recommendations
Health and Social Care Inspectorate	Inspection of services Authorization of certain services Issues permits for certain activities
Public Health Agency of Sweden	Public health Infectious diseases
Regional councils (21)	Primary care Specialised care Highly specialised care Emergency care
	Habilitation (Sometimes shared with municipality) Planning of dental care Specialist dental care
Municipalities (290)	Municipal primary care Social services

The table below provides a short overview of the structure, which is then presented in more detail (Table 1).

Government and government agencies

The government is responsible for the overall direction of healthcare, through legislation, principles and political guidelines regulating Swedish healthcare. The main legal framework is the Health and Medical Care Act (SFS, 2017a:30). The government also provides strategic financing, and issues grants and occasional funding to cover certain costs, e.g., those costs incurred during the Covid-19 pandemic. Further, it finances the different government agencies.

Examples of relevant government agencies are the National Board of Health and Welfare, responsible for issuing binding regulations and advisory recommendations in accordance with current legislation; the Health and Social Care Inspectorate that supervises healthcare and social care; and the Public Health Agency of Sweden that works to support public health and is responsible for infectious disease control measures.

Regions

The country is geographically organised into 21 self-governing local authorities, called regions. Regions are independently responsible for prioritising and organising healthcare provision within the political and legal framework set by the government (SFS, 2017a:30). The regions are responsible for the overall organisation of healthcare within their geographical jurisdiction, and they provide primary care, as well as emergency care and specialised care at hospitals (NBHW, 2019).

Basic healthcare that does not require specialist knowledge or resources is provided by primary care, typically at private or public local health centres. At these centres, planned and emergency medical assessments and care are provided, together with, for example, specialist nursing, maternity care and child health care. Other professions can include psychologists, dieticians, and physiotherapists (NBHW, 2019).

Healthcare requiring specialist knowledge and resources is provided at hospitals or by private clinics. Some highly specialised care is provided at designated hospitals.

A referral from primary care is not required to access specialist healthcare (NBHW, 2019). However, in practice, regions require referral for certain specialist care. These requirements differ across regions (Swedish Association of Local Authorities and Regions, 2023).

Municipalities and coordination

There are 290 municipalities in Sweden. Municipalities are independently responsible for organising and managing municipal primary healthcare. This typically includes district nurses, nurses, assistant nurses, occupational therapists and physiotherapists. Municipalities are responsible for the primary healthcare of elderly persons in care homes, and for persons with disabilities living in group homes or accessing daily activity services. It is possible for the region to transfer some of the healthcare responsibilities for persons living in their own home to the municipalities, through local agreements.

While municipalities do not employ doctors, regions and municipalities are by law required to collaborate around a patient to enable continuity and the best social support and healthcare possible in a joint effort. This collaboration is organised around a coordinated individual plan, included in social care legislation (SFS, 2001:453), as well as in healthcare legislation (SFS, 2017a:30).

Guiding principles for healthcare provision are safety, security and continuity. As a patient may need simultaneous or subsequent coordinated healthcare from several

healthcare providers across the region and municipality, it is possible to require a primary care provider under the Government Regulation on Healthcare (SFS, 2017b:80). This person is able to support secure, coordinated and safe healthcare with continuity.

Funding of healthcare and medicines

Healthcare is funded mainly through taxes levied by the regions and municipalities. Patients are generally listed at a local health centre. The essential remuneration is based on fixed capitation per registered patient, regardless of health needs. A smaller part is paid for performance-related bonuses, geographical location, and number of visits (Swedish Association of Local Authorities and Regions, 2021).

Patients pay a nominal fee when care is delivered by public healthcare or by private care providers who have a contract with the region. Without a contract, private healthcare is paid by the patient.

The cost of prescription drugs is subsidised. Prescription drugs are free of cost for children under the age of 18.

There is a threshold, or a high-cost scheme with a yearly high-cost limit, one for healthcare and one for medicines, that sets a limit to how much an individual has to pay. There is also a limit to how much a person has to pay per day when in hospital (1177.se, 2023).

Dental care

The regions are responsible for planning dental care, whether public or private. Specialist dental care is provided by the region, or privately through a local agreement. Care is free of charge until and including the year the person turns 23 (NBHW, 2021).

While dental care is subsidised, it is typically not included in the overall threshold scheme applicable for general healthcare. This means that dental care is more expensive than other healthcare for the general population. However, some defined groups, including persons with IDD, can apply to have their costs for dental care included in the general healthcare threshold scheme (NBHW, 2021).

THE ORGANISATION OF HEALTHCARE FOR PERSONS WITH IDD

The UN Convention on the Rights for Persons with Disabilities (UNCRPD) was signed by Sweden in March 2007 and ratified in December 2008. People with IDD are

supported in the community through the Social Services Act, the Social Insurance Code and the Act Concerning Support and Service for Persons with Certain Functional Impairments (abbreviated LSS). Focus will be on those accessing services through LSS. LSS is a rights-based law, listing ten measures, aiming to protect fundamental social rights for persons with IDD.

The aim of the legislation is to enable persons with IDD to “live like others”, with equal access to services available to the general population. All services should support the independence, self-determination, and participation of persons with IDD through full inclusion in society (SFS, 1993:387). This includes healthcare.

Healthcare and persons with IDD

Under the current legislation, Swedish persons with IDD access general healthcare on the same terms as everyone else. They are usually listed with a general practitioner at a health care centre (Nylander et al., 2014). However, for those living in group homes or accessing daily activity services, municipalities are responsible for providing primary healthcare, as described above. Municipal primary healthcare does not include healthcare that requires a doctor. In 2022, approximately 37% of persons accessing LSS services received healthcare from the municipality. The number was higher for those living in group homes, 66%. Most common measures were: testing, vaccination, medication, and testing and prescription of wheelchair (NBHW, 2023b).

The quality and safety of municipal healthcare provision are guaranteed by a medically responsible nurse employed for this purpose (SFS, 2017a:30).

Habilitation

Further specialised provisions are made for persons with IDD, i.e., through habilitation (SFS, 2017a:30). The responsibilities of providing habilitation are shared between municipalities and regions. Regions are responsible for all persons with IDD within the region, and municipalities are specifically responsible for those accessing municipal services.

The aim of habilitation is to enable persons with disabilities to function as well as possible, and to promote well-being and participation. Professions include, for example, psychologists, speech therapists, physiotherapists, and counsellors. While habilitation centres usually do not employ a nurse or a doctor, some do, and some engage a consultant doctor to aid collaboration with specialised medical care. When needed, habilitation centres

are able to assist in coordinating the joint health- and social care for a person with IDD.

However, the duties and organisation of the habilitation centres differ greatly across regions, regarding which professions are included, which groups are served, and the amount of support provided. (National support for clinical knowledge, n.d.). These differences are also evident in statistics on prescribed aids, and in how responsibilities are divided between the regions and the municipalities in local agreements (NBHW, 2023c).

Staff

Staff in LSS services for persons with IDD, such as group homes or daily activity services, support access to healthcare when needed. They do this together with the municipalities' medical professionals (Matérne & Holmefur, 2022; NBHW, 2018). Staff can be delegated by a nurse, doctor or dentist to give medicines (Handbook of Healthcare, 2020).

Trustee

Persons with IDD can apply for a legal representative, also called a trustee. The duties of a trustee are adapted to the needs of the person, and include any or all of: protecting rights, taking care of the client, and managing finances. ‘Taking care of the client’ includes ensuring that the person receives the best possible healthcare. A recent study shows that this part was the most neglected, due to lack of in-depth knowledge about the person (Hultman et al., 2022).

Healthcare for children with IDD

While this paper focuses on adults with IDD, we will briefly mention healthcare for children with IDD. There are large differences between child and adult habilitation centres, and between paediatric and adult healthcare. While children with IDD are supported through a healthcare team, often with a nurse as primary contact, adults are expected to manage a more fragmented system (SAHCSA, 2016). Therefore, persons with IDD might experience substantial gaps during transitioning from childhood to adulthood.

RESEARCH AND REPORTS ON HEALTH AND HEALTHCARE FOR PERSONS WITH IDD

It has been called into question if Swedish persons with IDD truly have equal access to healthcare, due to a lack

TABLE 2 List of recent research publications on health and healthcare for persons with IDD.

Title of publication	Type of publication	Topic	References
Residential care staff are the key to quality of health care for adults with profound intellectual and multiple disabilities in Sweden	Qualitative study, semi-structured interviews with residential care staff and managers in LSS-services	Municipality staffs' view of health care services for persons with PIMD (profound and multiple disabilities)	Matérne and Holmefur (2022). <i>BMC Health Services Research</i> , 22(1): p. 228
Association of intellectual disability with all-cause and cause-specific mortality in Sweden	Register study, population-based longitudinal cohort study	Health challenges and mortality in persons with IDD in Sweden	Hirvikoski et al. (2021). <i>JAMA Network Open</i> , 4(6): p. e2113014
Health care utilisation among older people with Down syndrome compared to specific medical guidelines for health surveillance: a Swedish national register study	Register study. A Swedish national cohort of older individuals with Down syndrome and register data of planned and unplanned visits to specialist health care	Older persons with Down syndrome report with few visits to planned specialist health care and frequent unplanned visits due to pneumonia, fractures and epilepsy	Ahlström et al. (2020) <i>BMC Health Services Research</i> 20(1): p. 949
End-of-life care among older cancer patients with intellectual disability in comparison with the general population: a national register study	A register-based study comparing pain medication prescription between older patients with cancer with and without IDD between 2006 and 2012	Patients with cancer are prescribed less pain medication if having an IDD compared to persons without ID	Seegerlantz et al. (2019). <i>BMC Cancer</i> 19:1040
High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder	Register study, population-based, comparison	Prevalence of obesity, diabetes and high blood pressure among individuals with and without IDD in a region in Sweden	Flygare Wallén et al. (2018). <i>Journal of Intellectual Disability Research</i> , 62(4): p. 269–280

of specialised knowledge and sufficient adjustments to meet the needs of patients with IDD (Nylander et al., 2014). There are also concerns that persons with IDD living in group homes may have reduced access due to a lack of individualised social support (Swedish Agency for Participation, 2020), limiting their possibilities to “live like others” (Björne, 2020).

The county council (now region) of Stockholm (2009) identified that it was difficult for primary care to maintain the required competence to meet the needs of patients with IDD. Hospital care, organised around medical professions lacked coordination, which did not benefit persons with IDD (Stockholm county council, 2009). The Swedish Association of Local Authorities and Regions (2018), the Swedish Disability Rights Federation (2022) and the Swedish National Association for People with Intellectual Disability (2022) all raise concerns about equal access to healthcare for persons with IDD, with regard to,

e.g., coordination, accessibility, funding, knowledge and reasonable adjustments (Table 2).

Research regarding health among Swedish persons with intellectual disability further paints a picture of health inequalities, caused by biological and social vulnerabilities, as well as inequities due to structural healthcare challenges. Several researchers describe the potential effects of a lack of healthcare that is timely, adequate and adjusted.

In a large study on mortality in young adults with IDD, researchers concluded that some of the excess mortality could be regarded as amenable to healthcare (Hirvikoski et al., 2021). The authors conclude that national guidelines that increase awareness and the implementation of scheduled health checks might improve the situation for persons with IDD, together with for example, accessible information and reasonable adjustments to improve healthcare encounters. In a study on mortality among older persons with IDD the authors also point out the need for better healthcare

planning and management, and to tailor healthcare to the specific needs of persons with IDD (Ng et al., 2017).

The results of longitudinal register studies including older persons with IDD showed different patterns in healthcare utilisation between persons with IDD and the general population, including psychiatric (Ahlström et al., 2020) and somatic (Sandberg et al., 2016) care. A higher degree of unplanned visits could indicate that there are barriers to planned access, potentially exacerbating health inequalities. This pattern of possible unequal access to healthcare was also discussed in studies on end-of-life care (Segerlantz et al., 2020). As an example, cancer patients with IDD were less likely to be prescribed pain medication or seen by a specialist. The authors concluded that symptoms might not be fully treated, with a negative impact on quality of life and end-of-life care (Segerlantz et al., 2019).

An interview study by Appelgren et al. (2022) provides one possible explanation for the difficulties in accessing planned healthcare. Nurses felt that they were unable to provide adequate care in a home-care context, and they had to fight for their patients' rights to timely and adequate care, particularly when this involved psychiatric care. They also felt inadequately prepared to meet the needs of persons with IDD, including a lack of training in individually adapted forms of communication.

Another explanation could be that persons with IDD depend on staff and managers in group homes to access healthcare (Matérne & Holmefur, 2022). This requires knowledge, planning and advocacy. This might also entail programs that promote healthy habits to prevent health inequities due to lifestyle challenges, such as the reported high prevalence of obesity and diabetes among individuals with IDD (Flygare Wallén et al., 2018).

DISCUSSION

Persons with IDD should have equal access to social and healthcare services, according to Swedish legislation and the UNCRPD, but it is apparent that this is not always the case (Nylander et al., 2014).

Decentralisation

The regional and municipal independence in managing, funding and organising healthcare described above, seems to lead to large differences in regional (SAHCSA, 2022) and municipal service provision. Further data and analyses are required to understand the reasons for this

(Johansson, 2021) and to remedy any differences that are not explained by demographic or other structural differences (SAHCSA, 2022). This should include data and analysis about the impact of healthcare provision for persons with IDD.

For example, one consequence of the decentralised system is that primary care and specialised care within and between regions use different digital systems. This leads to difficulties in sharing relevant information (SAHCSA, 2023). This might have an impact on persons with IDD who need a coordinated healthcare provision from different parts of the healthcare system.

Coordination

The fragmented healthcare system requires a significant amount of coordination, in particular for persons with complex needs, including persons with IDD (SAHCSA, 2016). Funding does not specifically cover the task of coordinating healthcare and social care. This task is expected to be fulfilled within the general budget. When coordination is seen as costly, there is a risk that it becomes less of a priority (SAHCSA, 2016).

A national focus on organising general healthcare from the perspective of the patient, rather than for the benefit of an efficient organisation (SOU 2018:39), might prove beneficial for persons with IDD.

Remuneration

The current system for remuneration is not adapted for persons with complex health needs, including persons with IDD. They might require longer time for a healthcare visit or a high degree of continuity in their contacts with healthcare professionals. The Swedish Association of Local Authorities and Regions (2018) suggests that the funding system requires change to accommodate for the needs of persons with IDD.

Health care professionals

Sweden has no specialisation for nurses or doctors within this field. In an interview study by the Swedish Agency for Health and Care Services Analysis (2016), some doctors found it difficult to meet the healthcare needs of persons with IDD due to a lack of knowledge among nurses and general practitioners. This does not imply that individual professionals necessarily lack in knowledge. However, competent healthcare provision for persons with IDD depends on individual engagement and experience rather

than resulting from formal requirements and systematic efforts. This might be a reason for the scarce opportunity for patients to get this specialised health care. For a person with IDD, this means that having access to a knowledgeable healthcare professional can be a result of chance. This situation is further exacerbated as direct support staff often lack in formal training, and therefore healthcare needs may go unnoticed and unsupported.

Health challenges

A higher degree of unplanned healthcare visits (Ahlström et al., 2020), shortcomings in end-of-life care (Segerlantz et al., 2019, 2020), together with premature deaths (Hirvikoski et al., 2021) and lifestyle challenges (Flygare Wallén et al., 2018) indicate that provision of healthcare for persons with IDD requires improvements. This would include training of healthcare professionals (Appelgren et al., 2022; Swedish Association of Local Authorities and Regions, 2018) and staff in LSS services (Matérne & Holmefur, 2022; Swedish Association of Local Authorities and Regions, 2018), as well as the development of national guidelines (Hirvikoski et al., 2021). An increased support in coordinating health- and social care would also be beneficial (SAHCSA, 2016), as would the possibility to follow the health of people with IDD at both individual and group levels (Swedish Association of Local Authorities and Regions, 2018).

CONCLUSION

Deinstitutionalisation promised equal access to services, including healthcare, to enable “living like others”. People with IDD are covered by the same benefits and access healthcare on the same terms as others. In addition, there are some specialised provisions in healthcare and social services. However, it has been argued that persons with IDD are excluded from equal opportunities through structural obstacles that go unrecognised (Björne, 2020) and healthcare that is not available on an equal basis (Nylander et al., 2014).

A decentralised healthcare system that requires extensive coordination seems to fail in providing safe and secure healthcare for Swedish persons with IDD, and the lack of continuity and specialised knowledge most probably contributes to the evident health inequalities. Future planning should be long-term and include the perspectives of persons with IDD and their supporting context to avoid future ethical failings (Sullivan et al., 2022), with the aim to make the general healthcare system accessible. This will include, e.g., structures for remuneration, training for healthcare professionals

and direct support staff and support for a coordinated healthcare and social services.

CONFLICT OF INTEREST STATEMENT

Both authors declare that they have no conflicts of interest.

ETHICAL APPROVAL

This research paper does not require ethical approval.

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SPECIAL ISSUE ARTICLE



Healthcare access and delivery for people with intellectual and developmental disability in the United States: Policy, payment, and practice considerations

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Abstract

Over 7.5 million people (approximately 2% of the US population) with intellectual and developmental disability live in the United States with the vast majority living in the community and accessing healthcare from the general healthcare system. For over two decades, there has been a national recognition that people with IDD experience poorer health outcomes and experience barriers in access to healthcare. We describe the important legal and financial frameworks that influence access to health care for people with IDD in the US, including a summary of major federal laws and insurance programs that have shaped the landscape of health and social care in the community, evolving trends in payment models, and the risks and benefits of these models. Further, we provide a description of health care delivery models which have been developed to support healthcare for people with disabilities including coordinated care delivery models. Clinical training and support for non-clinicians to attend to the particular health care needs of the population with IDD is critical yet is not widely available. Additionally, there remain significant access and quality gaps in healthcare for people with IDD. We conclude with a call for advances in health care quality, access and efforts to advance research and data collection to promote health equity for this population.

KEYWORDS

developmental disability, healthcare, intellectual disability, policy, practice

Abbreviations: ACA, Affordable care act; ADA, Americans with disabilities act; AADMD, American academy of developmental medicine and dentistry; DDNA, Developmental disabilities nursing association; DSP, Direct support professional; FFS, Fee for service; FQHC, Federally qualified care facilities; HCBS, Home and community based services; ICF-IDD, Intermediate care facility for individuals with intellectual disabilities; IDD, Intellectual and developmental disability; LEND, Leadership education in neurodevelopmental disabilities; LTSS, Long term supports and services; NIMHD, National institute on minority health and health disparities; PCORI, Patient centered outcome research institute; RIS, Residential information systems project; SSI, Supplemental security income; SSDI, Supplemental security disability insurance; UNCPRD, United Nations convention on the rights of persons with disabilities; US, United States.

HOW HEALTHCARE IS ORGANIZED IN THE UNITED STATES

The United States is home to over 330 million people (Census Bureau, 2022). National public health surveillance efforts have progressed in their ability to identify people with disabilities in the United States (CDC, 2020); however, these efforts do not yet allow for reliable identification of people with Intellectual and Developmental Disabilities (IDD) (Krahn, 2019). Most available prevalence estimates come from extrapolation of smaller scale studies. According to the US Residential Information Systems Project (2022), there were 7.43 million people of all ages with IDD in the United States in 2018, or 2.3% percent of the entire population. There are significant inequities in healthcare access and outcomes across geographic, social and demographic contexts in the United States (Tikkanen & Abrams, 2020). Inequities faced by people with IDD have been highlighted for decades (US Surgeon General, 2002). However, progress to address these inequities has been slow, in part because of the complex nature of health care delivery in the United States. This complexity makes it difficult to untangle and address the multi-layered influences and bias that drive and compound health disparities, including a higher prevalence of co-occurring health conditions, inadequate provider infrastructure, insufficient focus on health promotion, and inadequate access to quality health care services (Krahn et al., 2006). In July 2008, the United States signed the United Nations Convention on the Rights of Persons with Disabilities UNCRPD. The United States has not, however ratified the UNCRPD. The UNCRPD includes some similarities to the Americans with Disabilities Act (ADA) of 1990, which was established to protect people with disabilities living and working in the United States against discrimination in areas including public accommodations, transportation, and employment.

Below we discuss the major legal and financial frameworks that influence access to health care for people with IDD in the US, including a summary of major federal laws in Table 1.

The provision of health care in the US health care system is dependent upon health care financing choices, including the US's structure of health insurance coverage. This section provides an overview of the major sources of health care financing as a foundation for the discussion of health care provision. Health care financing in the United States relies predominantly on public and private insurers. Approximately 48.5% of Americans have private health insurance paid (or subsidized by) their employer as part of their overall compensation, 6.1% purchase private insurance on an individual basis, 8.6% are

uninsured, while the remainder are covered by public insurance programs such as Medicare and Medicaid (KFF, 2022). Existing research has not explored the relative utilization of each of these financing mechanisms by people with IDD, however public health insurance programs are disproportionately relied upon. The major publicly administered health insurance programs that fund health care for people with IDD are Medicaid and Medicare (Figure 1).

Medicaid, a public health insurance program, is a primary source of funding for healthcare for persons with IDD in the United States. Established in 1965, this program was developed to provide acute health care coverage to low-income Americans of any age and, with some modifications, remains in effect today. Crucially, Medicaid also is the primary payer for Long-Term Services and Supports (LTSS), ongoing assistance required by people with disabilities that in many other countries is financed outside health insurance coverage through a social care system. Unlike Medicare, which is administered and financed at the federal level, Medicaid is funded through a partnership between the federal and state government, with administration of the program handled by states. These state-administrative structures introduce significant variability into health care access in the United States. States have certain flexibilities to define rates for providers and to offer services that go beyond the minimum the federal government requires of every state Medicaid program. As an example of the variance in service financing, access and availability, the per enrollee spending by State in 2019 for adults with disabilities under the age of 65 ranged from \$11 049 per person per year to \$40 430 (KFF, 2021). To receive matching Federal funds, States must provide certain mandatory services to enrollees who are eligible for Medicaid, such as physician and hospital services, laboratory and diagnostic testing, home health, and access to nursing home. Other services, such as prescription drugs, personal care, are optional, but must be offered on a statewide basis to eligible Medicaid enrollees without waiting lists in every state that elects to offer them (CMS, n.d.-a, n.d.-b; MACPAC, n.d.-a, n.d.-b). However, the more robust home and community-based services (HCBS) used by many people with IDD are usually made available via optional waivers of traditional Medicaid coverage, permitting states to cap enrollment and maintain waiting lists for accessing service provision. Most US states maintain waiting lists for HCBS for at least some populations, with people with IDD in some states experiencing long waits for access to supports including community residential living support and an array of supports which may include expanded access to occupational, physical, speech and other therapies,

TABLE 1 Major US legislations that influence IDD healthcare access and use.

Year	Legislation	Summary	Relevance to healthcare for people with IDD
1965	Social Security Amendments Act of 1965 Medicaid	Established to provide acute and long-term health insurance coverage to low-income Americans of any age. Funded through Federal and State Cost Share. States have flexibility to expand their coverage beyond minimum program levels to include specialized support for people with disabilities. States are ultimately responsible for design and delivery of health services coverage. Administered by states under the authority of CMS	The largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities in the US. Eligibility and available services are state-specific. Insurance coverage and access to services are limited
1965	Social Security Amendments Act of 1965 Medicare	Federal health insurance program intended to provide for the medical needs of Americans aged 65 and older, regardless of their income/asset levels and medical history. In 1972, Medicare was expanded to include coverage of people with permanent disabilities under the age of 65 who received Social Security Disability Insurance (SSDI). Administered by CMS	A federal health insurance plan with consistent coverage across state lines. Eligibility determined by work history, receipt of disability support payments, or through other specific eligibility categories
1973	Section 504 of the Rehabilitation Act of 1973 (Section 504)	Prohibits programs that receive Federal financial assistance, as well as federally conducted programs and activities, from discriminating against individuals with disabilities	Healthcare that receives federal funding, including that paid for through public health insurance must be accessible to people with IDD if available to the general population
1981	Social Security Act: Omnibus Budget Reconciliation Act (OBRA) Section 2176	Created section 1915(c) of the Social Security Act authorizing Medicaid to provide Home and Community Based Services (HCBS). Prior to the passage of this Act, long term care was funded only if provided in an institutional setting	States are able to waive the institutional care requirement for long term supports and services, and expand community LTSS tailored to populations including people with IDD
1990	Americans with Disabilities Act (Title II and Title III)	Title II of the ADA applies to state and local government entities, while Title III applies to private companies that are engaged with the public—called “public accommodations.” Under Title III, discrimination includes the failure to make reasonable modifications, provide auxiliary aids and services, or remove architectural barriers, because such failures effectively prevent people with disabilities from enjoying the goods and services offered by a public accommodation	People with IDD are eligible to the rights and protections of the ADA. This does not apply in settings that are deemed private settings
1999	Olmstead Supreme Court Decision	A landmark civil rights decision asserted that the unjustified institutionalization of people with disabilities is illegal discrimination and that community settings should be available for people with mild to extensive support needs	Access to services in the community comes with the expectation that the majority of people with IDD who are living in the community will be accessing healthcare that is available to the general population
2000 (Re-authorized)	Developmental Disabilities Assistance and Bill of Rights Act	Funds a national network of grantees focused on promoting rights of people with IDD and their access to quality and effective supports in the community	Specific funding to improve the capacity of care providers to support people with developmental disabilities to live, learn, work and participate in their communities

(Continues)

TABLE 1 (Continued)

Year	Legislation	Summary	Relevance to healthcare for people with IDD
2010	Patient Protection and Affordable Care Act (ACA)	Among the provisions: Expanded Medicaid eligibility to adults with incomes at or below 138 percent of federal poverty level (subject to implementation decisions by states) Expanded options for Medicaid coverage of long-term services and supports with demonstration projects to better integrate Medicaid and Medicare for dual eligible population and expanded HCBS services. Established access to insurance options through state and federal “insurance marketplaces”	Expansion of Medicaid coverage included greater access to this insurance coverage for people with IDD. Variable uptake of options to expand coverage by state including specific eligibility categories that include or exclude particular disability categories such as autism
2014	HCBS Settings rule (42 CFR § 441.301 (c))	A federal rule requires that Medicaid HCBS settings are integrated in and support full access to the greater community, ensure individual rights of privacy, dignity and respect, and optimize autonomy and independence in making life choices. Implementation deadline for compliance by states has been extended several times and is currently March 2023	Ongoing effort to ensure that community based settings in which people with intellectual and developmental disabilities are supported through public funds do not have characteristics and limitations that would be seen in an institutional setting

equipment, and other long-term support needs (Burns et al., 2022).

In 42 states and the District of Columbia, Medicaid coverage is available to all recipients of Supplemental Security Income (SSI), one of the United States' two primary cash assistance programs for people with disabilities (MACPAC, 2022). This is one of the most frequent pathways for Medicaid eligibility and insurance coverage for people with IDD, though many adults with IDD also have Medicare eligibility via Social Security Disability Insurance (SSDI), the country's other primary cash assistance program for people with disabilities for which people with IDD can qualify either through prior work history or that of their parents (via the Disabled Adult Child pathway) (Social Security, n.d.).

As people with IDD have pathways into both Medicaid and Medicare coverage, many become “dually eligible,” adding further complexity to the administration of benefits and presenting challenges for effective care coordination. In recent years, the federal government has partnered with states to conduct demonstrations to improve care coordination for people with dual eligibility. However, most of these demonstrations have focused on the non-IDD population, with only one state (New York) specifically targeting people with IDD and several states entirely retaining the IDD population in a traditional, fee-for-service (FFS) funding model (MACPAC, n.d.-a, n.d.-b).

Managed care and alternative payment models

Both Medicare and Medicaid were historically predominantly publicly operated health insurance programs operating on an FFS basis, under which providers were reimbursed by the government for each service they provided. Motivated by the dual objectives of improving quality and reducing costs, both programs have increasingly shifted away from FFS models toward subcontracts with private health plans that provide managed care and alternative payment models under which health plans, providers or other entities take on some degree of ‘risk’ – financial responsibility for paying for services in exchange for a set funding stream that varies only based on enrollment rather than based on utilization (National Council on Disability, 2013). Under both Medicaid and Medicare managed care arrangements, enrollees may face more limited provider networks and tighter utilization management controls (e.g., restrictions on the types of care they may access) than under traditional FFS arrangements.

For people with IDD, the transition toward managed care presents potential risks and benefits. The intended

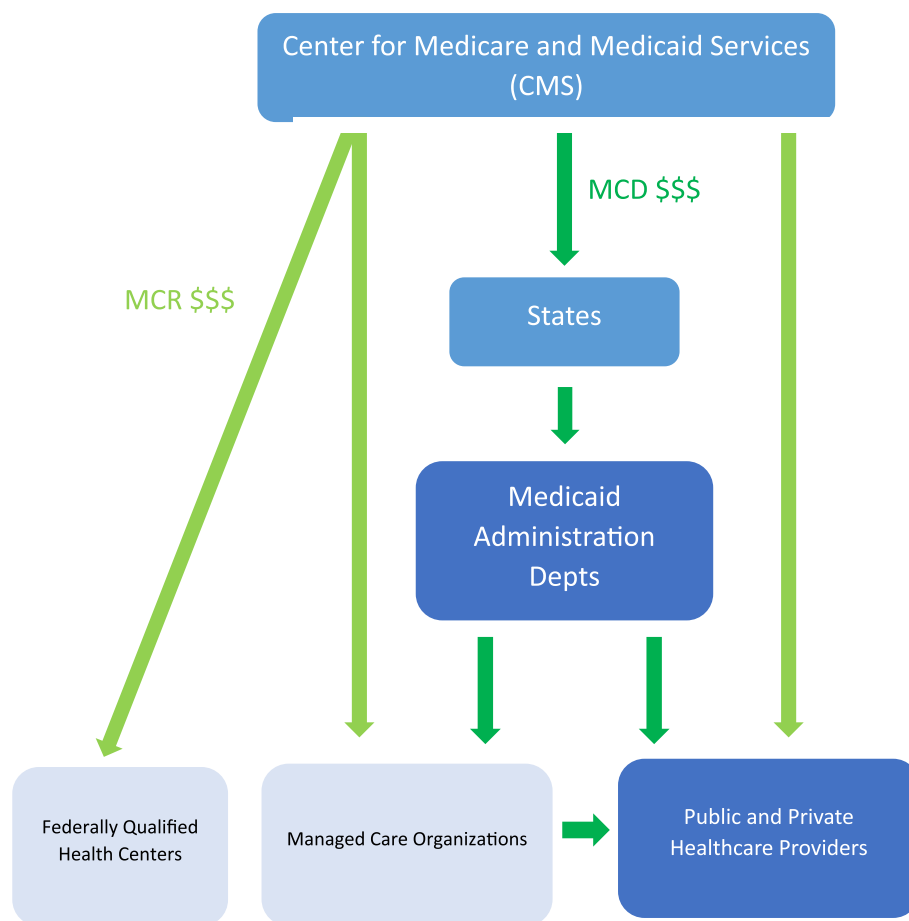


FIGURE 1 A simplified view of public funding of Healthcare for Americans with IDD. The U.S. government provides two primary public funding sources for healthcare, both administered by the federal government through the Center for Medicare and Medicaid Services (CMS). Medicare (MCR) funds are paid from the federal government directly to providers, Managed Care Organizations and federally administered outpatient care clinics, called Federally Qualified Health Centers. The Medicaid program (MCD) provides federal funds to each state on a cost-share basis to administer healthcare services (at each state's discretion) for their low-income residents.

benefits of managed care including reduction in use of nursing homes (Kumar et al., 2018) or other institutional setting in favor of greater focus on prevention and supports in the home and community hold promise. Most research on managed care has not specifically focused on the IDD population, though a small descriptive evidence base from Illinois suggests managed care transitions may reduce Emergency Department visits and inpatient hospitalization for people with IDD without reducing their overall healthcare costs (Yamaki et al., 2018, 2019).

However, health plans face significant incentives to enroll persons who are likely to be profitable to them relative to the capitated payment they will receive on their behalf. As health plans may not turn away enrollees, one available means they may choose to discourage enrollment of high-cost enrollees is “stinting” on types of care that are important to populations that are

predictably high-cost, such as by limiting access to HCBS or failing to include specialized providers in their networks. Although risk-adjustment and quality measures seek to mitigate these incentives, policymakers have limited experience applying these tools to people with IDD as compared to other populations (Auty et al., 2022; Layton et al., 2018, 2022). In 2017, approximately half of people with IDD were enrolled in managed care for acute healthcare benefits under Medicaid (Braddock et al., 2017). However, although many states have adopted managed care for LTSS for other populations, most states have “carved-out,” or separated, Medicaid LTSS benefits for people with IDD. However, recent managed care implementations have included LTSS for people with IDD into more managed care, ostensibly to improve coordination of care. Unfortunately, existing work has not examined the impact of the shift to managed care on people with IDD.



CURRENT STATUS OF HEALTHCARE FOR THE POPULATION WITH IDD IN THE UNITED STATES

Community living and long term services and supports for people with intellectual and developmental disabilities

The US Residential Information Systems Project (RISP) has provided data on the numbers of people living in various arrangements.

In 2019, 849 104 Long-Term Services and Supports (LTSS) recipients with IDD lived with a family member and 553 186 lived in other settings. Overall, 60% lived with a family member, 11% lived in their own home, 5% lived in a host or foster family home, 16% lived in a group home shared by six or fewer people with IDD, and 8% lived in larger IDD facilities, nursing homes or psychiatric facilities.

(Larson et al., 2022 p. 12)

Public funding for LTSS, including home and community-based services (HCBS), is primarily through Medicaid and the services available are designed and administered at the State level through contracts with public and private community and social service providers. Unpaid, natural supports, such as family members are often a source of support as well. It is estimated that less than half of adults with IDD are known to state agencies that provide IDD-specific long term support. Of those known to state agencies, an estimated 71% received LTSS funded through a Medicaid HCBS waiver and the remainder through other public and private insurance and direct funding (RISP, 2022). Unlike other populations of people with disabilities, who generally access institutional care through nursing homes, institutionalized people with IDD generally reside in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs) (Ne'eman et al., 2022). ICF-IIDs are historically large publicly operated state institutions. A growing number of states have closed their state institutions in favor of HCBS, with eighteen states no longer operating any of these facilities as of 2019 (Larson et al., 2022).

Living settings have implications for healthcare. In an analysis of preventive care among people with IDD in various residential settings, adults with IDD living on their own or in family homes were less likely to access preventive healthcare when compared to a more congregate setting in which staff and the residential services

provider is expected to support access to health care services (Bershadsky et al., 2012).

Delivery of healthcare for people with intellectual and developmental disabilities

The devolution of healthcare from being based within and associated with institutional settings specifically focused on custodial care for people with IDD to community-based settings has created both opportunities and challenges that have spawned unique modes of service. Unlike general population healthcare access in community out-patient settings, people with IDD may require a support system of caregivers and other personnel to work with physicians and other clinicians to provide the information necessary to evaluate the patient, to assure care coordination across all providers, and to execute care recommendations.

Unique outpatient delivery settings have evolved in multiple states to meet the specialized needs of the IDD community, although none have been created based on a coordinated or national strategy. These settings include grant-funded or state-subsidized multispecialty clinics. Other smaller state initiatives have included interdisciplinary teams of medical and behavioral specialists who actively collaborate during patient care (unlike multispecialty services, in which specialists are co-located but do not actively collaborate in real time.) However, given the expense and time requirements, interdisciplinary teams are usually reserved for a small number of patients with highly complex or refractory care issues (Crocker, 2006).

Because access to these specialized care teams is limited by geographic and staffing constraints (and because not all people with IDD require it), the majority of people with IDD obtain care from typical outpatient primary care practices or clinics dedicated to caring for Medicaid-eligible patients, such as Federally Qualified Health Centers (FQHCs). Primary care practitioners, or general practitioners, include family medicine practitioners, nurse practitioners, internists, and other licensed health care providers that provide general health and preventative care and are intended to coordinate specialty care needs. Established by the Affordable Care Act (ACA) of 2010, FQHCs are federally-subsidized clinics that provide preventive health, medical specialty, dental, and behavioral health services as well as transportation for health care services.

Despite the increased availability of community-based, Medicaid-funded services since the ACA was passed, there continue to be barriers to equitable care for persons with IDD. The majority of outpatient settings are not designed for physical accessibility of persons with

disabilities, and do not have the facilities such as wheelchair accessible scales or workflow processes such as flexible time to allow for communication of needed information and to achieve care goals (Lagu et al., 2014). In addition, in multiple surveys, over 90% of practitioners express discomfort and a lack of confidence in their ability to properly care for persons with IDD (Hemm et al., 2015; Phillips et al., 2004; Werner et al., 2013). One potential reason for this may be a paucity of research-based evidence within the medical literature that can serve as a basis for proper care (Dharampuriya et al., 2023). In a pre-ACA analysis of medical care cost expenditures, the primary driver of medical care costs (not including LTSS) in the population with IDD was prescription medication which was 28% higher in persons with IDD than in the general population, with the presence of secondary or chronic health conditions and poor mental health as being associated with high cost (Fujiura et al., 2018). Of note, a utilization analysis of South Carolina Medicaid recipients with IDD showed that almost 20% of their emergency visits, and 12% resultant hospitalizations, were due to issues that could have been managed in outpatient settings (McDermott et al., 2018).

Persons with IDD consequently suffer from serious healthcare disparities and avoidable health issues. Care differences are so stark that the American Medical Association has recommended that the population with IDD be federally designated as a Medically Underserved Population (Sullivan, 2011). In the United States, an underserved population designation could bring several benefits including the expansion of physician and dentist training in the care of people with IDD and scholarship or loan repayment incentives for clinicians to serve this population, and an expansion of research funding (Slashcheva et al., 2016).

Persons with IDD are increasingly experiencing newer delivery models incentivized by federal and state initiatives for improving the cost and quality of care of persons with chronic conditions. The ACA has incentivized the creation of "Health Homes," which fund comprehensive care management, coordination, individual and family support, as well as general LTSS care for low income persons with chronic conditions. Health Homes also provide funding for coordinated behavioral health and social service support. New Jersey received funding to create Health Homes dedicated to persons with IDD in 2014 (Primary Care Collaborative, 2022).

There are also Medical Home models that have been used for IDD care. Medical Homes are designated teams of specific healthcare providers accredited by both CMS and private payers, to provide medical services coordinated by a primary care provider. To date, there is scant evidence that the Health Home and Medical Home

models have improved efficiency and outcomes in persons with IDD. One study in OH of 207 residents of an intermediate care facility who received in-home medical home services had fewer hospitalizations than those receiving traditional care (Mills et al., 2022); however, additional research is needed. Major national efforts to establish quality measures are underway; outcomes of long term supports and services for adults with IDD are included in optional national reporting frameworks (CMS, n.d.-a, n.d.-b), and there are efforts to ensure that quality monitoring be in place as care models shift (United Healthcare, 2016).

The delivery of behavioral health services poses a unique challenge for persons with IDD in the U.S. Mental health services for the general population are administered in most states by agencies separate from those that administer IDD services, and are not tailored to supporting persons with IDD, despite the fact that up to 50% persons with IDD have been treated with psychotropic medication (often for management of behaviors that challenge) Costello et al. (2022), and those with IDD are 700% more likely to suffer the trauma of sexual abuse (Shapiro, 2018). As a result, it is difficult for persons with IDD to access emergency and inpatient care staffed with personnel experienced in their needs and that does not require long waiting for care (Pinals et al., 2022).

New technologies and delivery exigencies caused by the recent COVID pandemic have led to innovations that hold the promise of improving healthcare delivery for persons with IDD. These innovations, such as the use of telehealth, have shown early promise of value in small convenience samples, but if not regularly evaluated for effectiveness and accessibility, may result in less effective care and may not be accessible equally to all US citizens with IDD (Krysta et al., 2021; Valdez et al., 2021). To date, there are no clear guidelines for safe, effective implementation of any remote technologies. Remote health monitoring technologies present important opportunities to improve care delivery and access to high quality care, though some monitoring methods may pose significant ethical concerns that have yet to be fully addressed.

The COVID-19 pandemic has highlighted a number of additional challenges for people with IDD. People with IDD faced a disproportionate death toll owing to the greater vulnerability of congregate care settings (such as group homes and institutions) and the reliance of many people with IDD on in-person support. In addition, advocates report problems of discrimination in state and provider Crisis Standards of Care plans (Ne'eman et al., 2021), prompting intervention on the part of federal civil rights authorities to address disability discrimination in triage protocols (OCR, 2022). In an analysis of 2020 death certificate data, COVID-19 was the leading

cause of mortality among those with IDD, while it was the third leading cause of death among those without IDD (Landes et al., 2022).

Healthcare provider and direct support provider training

As supports for people with IDD have transitioned to the community, so has the expectation that healthcare providers should be prepared to meet the needs of this population. A growing body of evidence shows that the health needs of people with IDD are not well met in many community healthcare settings and promotes calls for enhanced training of health care practitioners (Ervin et al., 2014). Health Care providers are included in training cohorts in the 52 federally funded Leadership Education in Neurodevelopmental Disabilities (LEND) programs. These graduate level programs provide interdisciplinary clinical training and leadership development with the goal of improving the health of individuals who have, or are at a higher likelihood for developing, autism or related developmental disabilities. Several national organizations have undertaken efforts to address training gaps and establish population-specific expertise. The Developmental Disabilities Nursing Association (DDNA) has established an exam-based certification process that recognizes nurse's experience and knowledge in IDD. The American Academy of Developmental Medicine and Dentistry (AADMD) has also been working to advance training in medical schools, including working to include people with ID in clinician training.

In many cases, supports are provided by non-clinically trained direct support professionals (DSPs) or caregivers who are often best positioned to recognize signs that a person may need healthcare attention, but do not always have the knowledge, training, or available time to recognize signs that need medical attention, take appropriate action, to support coordination of care across healthcare settings, or to provide ongoing health support such as medication or other therapies. The workforce of DSPs in the US is, as in many countries, experiencing a serious challenges including significant turnover and high rates of positions that are not filled. This turnover creates significant challenges in the ability to adequately train personnel to support and ensure attention to ongoing or emerging healthcare needs. New approaches for health monitoring, telehealth, and those that combine monitoring with decision support (Dharampuriya & Abend, 2022) hold promise to make the HCBS workforce more efficient and effective in health support (Table 2).

KEY CHALLENGES AND FUTURE DEVELOPMENTS

The United States presents a complex and variable picture for health care access and delivery with disproportionately large barriers to access and quality care for marginalized populations including the population with IDD. While the overall picture is challenging, there is movement and passion to address the healthcare delivery gaps which contribute to poorer outcomes for people with IDD.

Foundational work must be done within the US public health surveillance systems to routinely and effectively be able to identify people with IDD within national datasets. This work is underway (I/DD Counts, n.d.), with several federal agencies engaging in developing methods to better identify the population in national surveys and in administrative data. It is also essential to build a research evidence base for proper healthcare practices in order for any provider training curriculum to be useful. In addition, more work is needed to build a body of rigorous health services research on the impact of health systems changes on people with IDD as a distinct population. Although people with IDD benefit from substantial descriptive research on their distinct needs, relatively little research has employed methods of causal inference to understand the impact of policy changes on this population.

Specialty societies such as the Developmental Disabilities Nursing Association and the American Academy of Developmental Medicine and Dentistry have been active in advocating for greater attention to this population in health care. Achieving a designation of “medically underserved population” could serve to bolster these efforts through focused attention on building provider capacity. Although the MUP designation has not yet been achieved at the federal level, in 2019 the population with IDD was identified as a priority population in the federal Patient Centered Outcome Research Institute (PCORI) for comparative effectiveness research. In September 2023, the United States National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. While holding promise for expanded research opportunities, this does not achieve the needed Medically Underserved Population which would be needed to directly expand the provision of clinical and preventative care to the population with IDD.

As provider networks shift and expand in the United States, integrated care delivery models are being developed in which funds for both acute and long-term supports and services are bundled and available in a

TABLE 2 Selected publications.

Title of publication	Type of publication	Topic	Reference
Medicaid services for people with intellectual or developmental disabilities – evolution of addressing service needs and preferences	Policy brief	An examination of current policy issues and use of Medicaid by the population with intellectual and developmental disabilities. The paper emphasizes long terms supports that can be accessed through Medicaid	https://www.macpac.gov/publication/medicaid-services-for-people-with-intellectual-or-developmental-disabilities-evolution-of-addressing-service-needs-and-preferences/ Plain Language Version available at: https://www.macpac.gov/wp-content/uploads/2021/01/Plain-Language-Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf
National Council on Disability Health Equity Framework (2022)	Policy Brief	Current and recommended policy to promote equity for people with disability	https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf
Toolkit for advocates on healthcare and the transition to adulthood	Toolkit	Practical commentary and guidance for youth and adults and advocates to promote better healthcare access outcomes	https://autisticadvocacy.org/2014/07/asas-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/
Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities	Government Report	Summary of priorities and action steps needed to create a data infrastructure which will allow monitoring and improvements in health and long term support outcomes for people with IDD	Dhopeswarkar, R., Rotondo, C., Jiménez, F., Ryan, S., Karimi, M., Plourde, E., and Dullabh, P. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. July 26, 2022. https://aspe.hhs.gov/sites/default/files/documents/dab8370bf95a35d678e6968de86f9ecd/idd-opportunities.pdf
Healthcare Delivery	Textbook Chapter	Healthcare Delivery (Section 7) provides a detailed description of healthcare delivery in the United States context	Healthcare for People with Intellectual and Developmental Disabilities across the Lifespan 3rd ed. Rubin IL, Merrick JL eds. Paul R Brookes, 2016



capitated payment model with greater emphasis in coordination to enhance care quality and contain costs. This holds promise for achieving both better coordination of care and cost savings; however, the potential for a shift back to a more medical model of care delivery raises concern and a need for close monitoring of satisfaction and life outcomes for people who receive supports in these models. Similarly, while the transition away from FFS healthcare presents opportunities for enhanced care coordination, there also exists substantial risks for predictably high-cost populations such as people with IDD that have yet to be adequately addressed, even as the transition to managed care proceeds on an extremely rapid basis.

The principles of choice and self-determination are strongly held values in both the disability supports arena (person-centered planning) and in health care (patient centered care). As these principles become more fully actualized in the delivery on long term community supports and health care, there are opportunities to ensure that people are supported to exercise and express their own choices in health care delivery by making use of supported decision-making models.

Finally, people with IDD should be further integrated into research and subsequent training for health care providers and into the design of effective, efficient health care systems of support.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interests to disclose.

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SPECIAL ISSUE ARTICLE



Health systems, health policies, and health issues for people with intellectual disabilities in England

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Abstract

People with intellectual disabilities face health disparities, including in high-income countries such as the United Kingdom, despite publicly funded healthcare. This paper describes the healthcare system in England (a nation of the United Kingdom) for the general population, and more specifically for people with intellectual disabilities. Key legislation that impacts the lives of people with intellectual disabilities, such as the UK Equality Act 2010 (<https://www.legislation.gov.uk/ukpga/2010/15/contents>), the Mental Capacity Act 2005 (<https://www.legislation.gov.uk/ukpga/2005/9/contents>), and the UN Convention on the Rights of Persons with Disabilities, and its implementation in the United Kingdom, is discussed. The role of deinstitutionalization and the shift to living in the community for people with intellectual disabilities is also discussed. Programmes that have been implemented to address the health disparities experienced by people with intellectual disabilities are reviewed. Finally, the recent changes to healthcare organization in the UK, the COVID-19 pandemic, and the implementation of the Valuing People white paper are discussed.

KEYWORDS

health care, health inequities, health policy, intellectual disabilities, United Kingdom

INTRODUCTION

The United Kingdom (UK) is a constitutional monarchy that is composed of four devolved nations: England, Wales, and Scotland; and Northern Ireland. (Ministry of Justice, 2022) Each nation has its own healthcare system, thus for this paper, I will focus on the healthcare system in England. The National Health Service (NHS) was established in 1948 and is localized to each nation and provides comprehensive

healthcare to all residents of the UK that is generally free at the point of access (NHS, 2013). People with intellectual disabilities receive much of their care from generalist community-based providers and are less likely to receive healthcare in an institutional setting (Mansell et al., 2007). Despite similar availability of healthcare, adults with intellectual disabilities have a lower life expectancy and may be more likely to die from avoidable and easily treatable causes. Recent programmes in the UK aim to overcome these inequalities (National Institute for Health and Care Excellence, 2021). This article will focus on the health system, both generally and for people with intellectual disabilities, in England, although the health

Abbreviations: NHS, National Health Service; ICB, Integrated Care Board; ICP, Integrated Care Partnership; ICS, Integrated Care System; UN, United Nations.

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system in other nations in the UK (i.e. Scotland, Wales, and Northern Ireland) is similar. Legislation discussed frequently applies to all of the UK.

In 2021, the population of England was estimated to be 56 490 048 residents (Office for National Statistics, 2022). In spite of universal health coverage, only 55.7% of the general population was included in recent (2021–2022) health statistics regarding intellectual disabilities prevalence in England. Of those included in these statistics, 0.5% of patients were recorded by their general practitioner as having intellectual disabilities (NHS Digital, 2022). Under the Equality Act, 2010, the public sector has a legal duty to provide services to people with disabilities, including intellectual disabilities, and to make reasonable adjustments (Public Health England, 2020a). Some of these reasonable adjustments may include including clear, simple, and possibly repeated explanations of medical processes and treatments, assistance with attending medical appointments enabling people with intellectual disabilities to access comprehensive publicly-funded healthcare. In accordance with the Mental Capacity Act (2005) there may be a need for people with intellectual disabilities to have accommodation such as having another adult consent on their behalf for medical procedures, if the clinician decides that the person with intellectual disabilities may have difficulties with consent.

HEALTH SYSTEM IN ENGLAND

The National Health Service was established in 1948 to provide comprehensive, free at the point of use care to UK residents (NHS, 2013). In England, funding for the NHS is voted on by the House of Parliament, and the money goes to the Department of Health and Social Care. The department is overseen by the Secretary of State for Health (Department of Health and Social Care, 2013). The majority of funding goes to NHS England. Prior to July 2022, many (although not all) funds went to Clinical Commissioning Groups which purchased and commissioned care (from both public and private/third party providers) and then the funds were received by NHS trusts and NHS providers (Department of Health and Social Care, 2013). Some, but not all health and social care were, and are still, monitored by the Care Quality Commission, an independent body that ensures national standards of quality and safety are met (Department of Health and Social Care, 2013).

LEGISLATION REGARDING THE HEALTH SYSTEM IN ENGLAND

Under the Health and Social Care Act, 2022, Clinical Commissioning Groups were replaced by Integrated Care

Systems (ICSSs), composed of an Integrated Care Board (ICB) and an Integrated Care Partnership (ICP). ICBs are responsible for commissioning care and are accountable to NHS England, while ICPs have some membership from ICBs and integrate NHS and local authorities (who may provide social care and public health) to provide care (King's Fund, 2022). These new functions were established with the aim of better integrating health and social care locally. Such meetings allow providers to provide more joined-up care planning and delivery across sectors. As of July 1, 2022, there were 42 Integrated Care Systems (ICSSs) in England, highlighting some of the complexities of delivering care at the local level (NHS England, 2022). The aim of establishing ICBs and ICPs was to deliver more integrated care to patients and service users, allowing for more communication and collaboration between hospitals and health organizations, social care providers, and the community and voluntary sector. Especially since adults with intellectual disabilities may receive care from numerous providers, having structures that allow for greater communication and collaboration across organizations and providers may allow for more joined-up care, and ultimately better health outcomes (King's Fund, 2022).

At the local level, Integrated Care Systems (ICSSs) in conjunction with their constituents, commission primary and specialist healthcare. Primary care is mainly delivered by general practitioners (non-specialist physicians) and associated staff such as nurses, nursing assistants, and community pharmacies (Thorlby, 2020). General practitioners may refer patients to specialized care, which may be ambulatory or in-patient, and is delivered at public hospitals with different levels of specialization and different catchment areas. Most care delivered by the NHS is free at the point of contact, with the exception of some services (i.e. co-payments for prescription medications, fees for dispensing optometry products).

Legislation regarding people with intellectual disabilities

The United Nations (UN) Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly on December 13, 2006, and its entry into force was May 3, 2008 (United Nations, 2007). The UK signed the convention on March 30, 2007, and the UK ratified the convention on June 8, 2009. In 2011, the Office for Disability Issues (HM Government, 2011) issued a report on how the UK government was meeting the UN Convention, especially in light of the Equality Act, 2010. The UN Committee on the Rights of Persons with Disabilities held an inquiry as to whether the UK was fulfilling its requirements under the Act in 2016, and the

UK issued a follow-up report with its progress meeting each article of the Convention in 2021 (Department for Work and Pensions, Disability Unit, 2021).

Much of the legislation in the UK relevant to people with intellectual disabilities comes from the Equality Act, 2010, which outlines the protected characteristics of people that cannot be discriminated against. These characteristics include age, gender reassignment, disabilities, marriage and civil partnership, race, religion or belief, sex, and sexual orientation. This legislation specifically addresses reasonable accommodations in housing, employment, provision of health and government services, education, and transport, and defines the forms of discrimination that are not allowed. The Equality Act, 2010 defines disabilities as: a person is disabled if he or she has a physical or mental impairment resulting in substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. 'Long-term' means that the effect of the impairment has lasted or is likely to last at least 12 months. This definition applies when determining whether someone is disabled for the purposes of this Act.

There are other pieces of legislation in the UK that apply to individuals with intellectual disabilities, and provision of health and social care. The Mental Capacity Act, 2005 covers processes for obtaining consent if the person is unable to provide consent, such as intellectual disabilities. Another key piece of legislation with regards to provision of healthcare is the Health and Social Care Act, 2012, which made major structural changes to the NHS. Further changes to healthcare provision were made by the Health and Social Care Act, 2022.

THE ORGANIZATION OF HEALTH AND SOCIAL CARE FOR ADULTS WITH INTELLECTUAL DISABILITIES IN ENGLAND

Historically, much, but not all, of the healthcare for adults with intellectual disabilities was delivered as part of publicly funded institutions. However, beginning in the mid-twentieth century, there was a shift to delivering healthcare to adults with intellectual disabilities within the community, resulting in better health outcomes (Emerson & Hatton, 1996).

Deinstitutionalization and its impact on the lives of adults with intellectual disabilities

In recent decades, there has been a shift from institutionalization of people with intellectual disabilities to community living in many European countries, including the

UK (Mansell et al., 2007). In the UK, including England, in recent years healthcare for adults with intellectual disabilities has been delivered through a mix of state (National Health Service or NHS) funding and private and benefits funding.

In 1948 with the founding of the NHS, much of the responsibility for caring for people with intellectual disabilities was transferred to NHS-run hospitals (Mansell et al., 2007), although some people with intellectual disabilities lived in the community. By the 1960s, there was growing public recognition regarding some of the problems of institutional care, and in 1971 there was an increasing focus to increase outpatient and community-supported care for adults with intellectual disabilities (Mansell et al., 2007). In the 1960s and 1970s when NHS Mental Handicap hospitals were decommissioned, initially, people with intellectual disabilities with less support needs were transferred to existing community supports like hostels and supported group housing or living with family or independently (Emerson & Hatton, 1996). The focus at the time was on residential support for people with more severe or complex needs (Emerson & Hatton, 1996), however since the 1990s advocates for community inclusion demonstrated in during this time that people with intellectual disabilities, even with complex needs, can live in the community with appropriate supports (Mansell et al., 2007). By the 1980s and 1990s, the community inclusion model, led by advocates with physical and sensory disabilities, was more widely adopted, and resulted in a greater focus on community inclusion (Mansell et al., 2007).

The shift away from institutional care has had positive impacts on the lives of adults with intellectual disabilities. In the 1990s, Emerson and Hatton (1996) found in their review that there was more engagement in activities, including social activities, and greater contact with staff in supported housing than institutional care, more social contact including with family members, and greater life satisfaction. Similarly, Hamlin and Oakes (2008) found that community based residential care led to greater social contact, while provision of care was still similar. By 2004, fewer individuals with intellectual or developmental disabilities received non-profit or for-profit institutional care (28% and 29%), and only 12% of individuals with intellectual disabilities were residing in NHS-funded hospitals (Emerson, 2004).

Although people with learning disabilities are increasingly living in the community, they receive a hybrid model of generalist and specialist support. Much primary care is delivered by community-based general practitioners and other providers at general practitioner surgeries and community pharmacies, with more specialized medical care delivered at hospitals. Community-based learning disabilities nurses, a profession that is unique to the UK and the Republic of Ireland, also provide and coordinate much



community-based care for adults who are registered with their general practitioner as having an intellectual disability (Breau et al., unpublished data). The aim of this unique health professional role is to provide preventive care and coordinate healthcare for this group.

Despite the growing push for adults with intellectual disabilities receiving care and support in the community, some adults with intellectual disabilities are still hospitalized long-term, for multiple reasons. After the Winterbourne View Hospital scandal in 2011, when it became public that some residents were abused at this private hospital and staff were prosecuted, the government introduced a plan to encourage health and social care to work more closely together, and for the CQC to more closely and thoroughly investigate facilities providing care (Department of Health, 2012). In 2015, the Building the Right Support policy paper was issued, to further push for more joined-up services for adults with intellectual disabilities (Local Government Association, ADASS, & NHS England, 2015). Given the recent legislation (Health and Social Care Act, 2022) calling for greater integration of health and social care, these developments may result in more integrated care and ultimately better health outcomes for people with intellectual disabilities.

Health care provision for adults with intellectual disabilities

The NHS provides general and specialist care for adults with intellectual disabilities similar to the general population. However, in recent years, there have been programmes that have been commissioned in collaboration with the NHS with the aim of reducing health inequities. These programmes include the Learning Disabilities Mortality Review Programme and the Oliver McGowan Mandatory Training programme to ensure adults with intellectual disabilities are prescribed medication appropriately, and additional training for healthcare providers. It is important to note that frequently the term for intellectual disabilities used by the UK government and NHS is “learning disabilities”, which includes individuals with intellectual disabilities.

In 2013, the Department of Health established the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities to investigate the premature deaths of people with intellectual disabilities especially in southwest England (Kennedy et al., 2021). Consequently, in 2017, the Learning Disabilities Mortality Review Programme was commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, with the aim of investigating the deaths of people with intellectual disabilities and/or autism, and the health and social care they

received (NHS, n.d.). This programme aims to improve care, reduce health inequalities, and prevent early deaths in people with intellectual disabilities and autism, and has carried out over 9000 reviews to date. A 2018 report found many of these deaths were attributed to preventable and treatable conditions: sepsis (11% of deaths), constipation, dysphagia and associated aspiration pneumonia (16%), and cancer (14%), including cancers for which population-based exist (NHS England, NHS Improvement, 2019).

Other recent initiatives to enhance the health care provided include the Learning Disabilities Core Skills Education and Training Framework (Skills for Health, Health Education England and Skills for Care, 2016) that was established to provide training to staff providing care to people with intellectual learning disabilities. It draws from existing legislation, and provides knowledge and skills to staff who have contact with people with intellectual disabilities. This framework was updated in 2019, and consists of three levels of training: training for health and social care staff and family members who may make decisions about care for people with intellectual disabilities, health and social care staff who may not be in a decision-making role but provide care to adults with intellectual disabilities, and staff who need a general awareness about intellectual disabilities. (Skills for Health, Health Education England and NHS England, 2019). While this training is not legally binding by legislation, it is highly recommended and promoted to health and social care staff by the NHS and affiliated organizations.

Despite this initiative, prescribing of certain medications, such as antipsychotic medications, is greater in people with intellectual disabilities: 14.5% of people with intellectual disabilities were prescribed this medication in 2021–2022, compared to approximately 0.9% of the general population (NHS Digital, 2022). In response to the 2016 death of a teenager, Oliver McGowan, who had autism and had antipsychotic medication administered improperly, and the resulting campaign led by his mother, the Oliver McGowan Mandatory Training programme was implemented and a report was commissioned by NHS Health Education England (2023). This programme aimed to train healthcare professionals on proper psychotropic medication prescribing for people with intellectual disabilities and/or autism (National Development Team for Inclusion, 2022).

In 2001, the Valuing People White Paper was released, outlining several key policies and programmes for individuals with intellectual disabilities (Department of Health, 2001), including the development of Partnership Boards. This report was followed up in 2010 with the publication of the Valuing People Now Report (Department of Health, 2010), although there has been little policy action on this topic since then. However, given the recent stories in the media regarding people

TABLE 1 Key recent studies regarding the healthcare system for adults with intellectual and disabilities.

Author and year	Title of publication	Type of publication	Aim	Reference
Bur et al. (2021)	The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review	Integrative review	The objective of this review was to systematically identify, appraise and synthesize the best available evidence for the impact of intellectual Disability Nurse Specialists in comparison with an alternative or no intervention	Bur, J., Missen, K., & Cooper, S. (2021). The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review. <i>Nursing Open</i> , 8: 2018–2024
Cooper et al. (2018)	Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study	Cross-sectional observational study (in Scotland)	The aim of this study was to measure the management of long-term conditions within primary health care for adults with intellectual disabilities, and to compare this with the general population, using indicators of best practice from the Quality and Outcomes Framework	Cooper, SA, Hughes-McCormack, L., Greenlaw, M., McConnachie, A., Allan, L., Baltzer, M., McArthur, M., Henderson, A., Melville, C., McSkimming, P., & Morrison, J. (2018). Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study. <i>Journal of Applied Research in Intellectual Disabilities</i> . 31(S1): 68–81
Glover et al. (2017)	Mortality in people with intellectual disabilities in England	Data linkage study (in England)	The authors identified the rates and patterns of mortality of people living in England and identified by their GP as having intellectual disabilities, in relation to age, sex and causes of death	Glover, G., Williams, R., Heslop, P., Oyinlola, J., Gray, J. (2017). Mortality in people with intellectual disabilities in England. <i>Journal of Intellectual Disability Research</i> . 61(1): 62–74
Heslop et al. (2014)	The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study	Quantitative	Aim of Confidential Inquiry to establish how similar or different circumstances of death in people with intellectual disabilities were to people without intellectual disabilities	Heslop, P, Blair, P, Fleming, P, Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study <i>Lancet</i> . 383: 889–895
Paton et al. (2016)	Quality of prescribing of antipsychotic medication for people with intellectual disability under the care	Quantitative	To determine the prevalence and quality of antipsychotic prescribing for people	Paton, C., Bhatti, S., Pirandare, K., Roy, A., Barnes, T. (2016). Quality of prescribing of antipsychotic medication

(Continues)



TABLE 1 (Continued)

Author and year	Title of publication	Type of publication	Aim	Reference
	of UK mental health services: a cross-sectional audit of clinical practice		with intellectual disability	for people with intellectual disability under the care of UK mental health services: a cross-sectional audit of clinical practice. <i>BMJ Open</i> , 6: e013116

with intellectual disabilities being placed long-term in in-patient situations, NHS England, as part of its Long-Term Plan, unveiled the Mental Health, Learning Disability and Autism Inpatient Quality Transformation Programme in 2022 to help address these issues. (NHS England, [n.d.](#)). It remains to be seen if some of these policy actions will be translated into actions addressing the health inequalities experienced by people with intellectual disabilities.

KEY RECENT STUDIES REGARDING THE HEALTH AND SOCIAL CARE SYSTEM FOR ADULTS WITH INTELLECTUAL DISABILITIES

In Table 1, five articles that address the health of people with intellectual disabilities, are summarized to provide greater information about key issues affecting healthcare provision in adults with intellectual disabilities in England. These articles provide information regarding some of the contemporary health issues raised in this manuscript, including the role of the learning disability nurse in the UK, greater information and data on mortality patterns for adults with intellectual disabilities in England, and data on adults with intellectual disabilities' experiences accessing health care, including accessing primary care and overprescription of anti-psychotic drugs (Bur et al., 2021; Cooper et al., 2018; Glover et al., 2017; Heslop et al., 2014; Paton et al., 2016).

CONCLUSIONS AND FUTURE DIRECTIONS

Healthcare in England is often provided free at the point of access, and there are generally, with the exception of Learning Disabilities Nurses, limited specialist health services for adults with intellectual disabilities. Recent legislation introduced in the United Kingdom, the Health and Social Care Act, 2022, may have an impact both on how health care is organized and commissioned and will,

through ICBs and ICPs, lead to more collaborative planning between the health and social care sectors. Other initiatives in England, such, Oliver McGowan Mandatory Training programme to monitor medication prescribing to people with intellectual disabilities, and training for health and social care staff may have an even greater impact in the coming years.

The COVID-19 pandemic has also had a major impact on the health of adults with intellectual disabilities. Due at least in part to this health challenge, Public Health England was disbanded in 2021 and replaced with the UK Health Security Agency and the Office for Health Improvement and Disparities (Public Health England, [n.d.](#)). While the latter aims to improve health and reduce health disparities, it remains to be seen if this agency facilitates reducing the health disparities faced by adults with intellectual disabilities (Office for Health Improvement and Disparities, [n.d.](#)). In addition, the death rate from February 2020–June 2020 for COVID-19 for adults who were identified as having intellectual disabilities was 240 per 100 000, a rate 2.3 times higher than the general population (Public Health England, 2020b). Given some of the other challenges people with intellectual disabilities faced with accessing health and educational support (e.g. Jeste et al., 2020) and the impact of COVID-19 on the health of people with intellectual disabilities more generally (Totsika et al., 2021), it remains to be seen the long-term impact of the COVID-19 on healthcare provision for adults with intellectual disabilities. Additionally, given the increasing focus of the NHS on providing preventive care and chronic disease management, and moving away from acute care, the health disparities faced by this group may be reduced.

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CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest.

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SPECIAL ISSUE ARTICLE



Intellectual disability healthcare in Australia: Progress, challenges, and future directions

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Abstract

People with intellectual disability experience some of the greatest health disparities in Australia. Individuals are expected to access mainstream health services that are ill equipped to meet their needs. The Australian government has made recent commitments to improve the healthcare of people with intellectual disability. This article describes the Australian health system and how it responds to the needs of people with intellectual disability. It draws on examples of advances in policy, inclusion, and service development, achieved through concrete and persistent systemic advocacy, to discuss emerging evidence on the delivery of healthcare to people with intellectual disability in Australia. The article also highlights immediate priorities including increasing the uptake of health assessments, building the capacity of our health workforce, and responding to the needs of people with intellectual disability in COVID-19 outbreaks or other natural disasters. Intellectual disability healthcare is at a dynamic point in Australia with commitment and funding from government to lead to change. It is critical that momentum in health services development is maintained to enable improved health outcomes for people with intellectual disability.

KEYWORDS

Australia, healthcare policy, health services, intellectual disability, service development

INTRODUCTION

Australians with intellectual disability have a very poor health profile, and experience some of the greatest health

disparities in Australia, dying up to 27 years earlier than people without intellectual disability (Florio & Trollor, 2015). Much of this health gap is preventable with state-level reviews of the deaths of people with disability finding 38%–53% of deaths are avoidable (Office of the Public Advocate, 2016; Trollor et al., 2017). This is misaligned with Australia's commitment to the United Nations Convention of the Rights of Persons with Disability (UNCRPD) and optional protocol, which were

Abbreviations: COVID-19, Coronavirus 2019; CHAP, Comprehensive health assessment program; COAG, Council of Australian Governments; GP, General practitioner; NDIS, National disability insurance scheme; P=CEP, Person-centred emergency preparedness.

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signed and ratified in 2008 and 2009 (Australian Government Department of Social Services, 2022).

The ways in which the Australian health services have responded to the needs of people with intellectual disability have changed considerably over time. Historically, people with intellectual disability were placed in large institutions, segregated from society. These institutions were responsible for both disability and health support and were funded by a mix of government and charitable sources (Cocks, 1998). Similar to movements across North America and Europe, Australia began deinstitutionalisation and shifted towards community living in the 1970s and 1980s. However, the Australian health system was unprepared and ill equipped to meet the healthcare needs of people with intellectual disability on transition to community living (Beange, 1996).

Over time, repeated efforts from individuals and organisations raised awareness of this issue and advocated for systemic change to the way healthcare is delivered to people with intellectual disability. A key feature of this advocacy has been leadership by people with intellectual disability, their support networks, and the work of the Council of Australian Governments (now replaced with the National Cabinet). The need for change has been highlighted in successive versions of the National Disability Strategy (Commonwealth of Australian Governments, 2011; Commonwealth of Australia Department of Social Services, 2021) and was most recently exposed in an Australian government-initiated investigation by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission), which exposed 'systemic neglect' in healthcare for people with intellectual and other cognitive disabilities (Disability Royal Commission, 2020). In response to these findings and years of ongoing advocacy, the Federal Government partnered with stakeholders to develop and launch a National Roadmap for Improving the Health of People with Intellectual Disability (The National Roadmap) in 2021. The National Roadmap sets targets for reforms across the health system over a 10-year period (Department of Health and Aged Care, 2021). The Federal Government has also committed to enduring funding for a newly funded National Centre of Excellence in Intellectual Disability Health and \$20 million in research funding to improve health of people with intellectual disability.

The aim of this article, whose author group comprises an advocate with lived experience of intellectual disability, clinicians, and researchers is to describe:

- The experience of Australians with intellectual disability accessing health care.

- The Australian healthcare system and how it responds to the needs of people with intellectual disability.
- Emerging evidence on the delivery of healthcare to people with intellectual disability in Australia.
- Key challenges, reflections on best practices, and future developments in this area.

THE EXPERIENCE OF AUSTRALIANS WITH INTELLECTUAL DISABILITY

Australians with intellectual disability represent a diverse range of people with varied backgrounds and experiences. Australia has a population of almost 26 million people (Australian Bureau of Statistics, 2022) and it is estimated that 1.8% have an intellectual disability (Wen, 1997). However, the exact figure is hard to determine because of differing definitions of intellectual disability and data collection methods. Evidence suggests higher prevalence of intellectual disability in Australia's First Nations people (also referred to as Aboriginal and Torres Strait Islander peoples); however, this population group are at a lower likelihood of receiving disability support and healthcare due to numerous reasons including discrimination and a lack of culturally safe services (Armstrong et al., 2023; Barney, 2021). People with intellectual disability from diverse backgrounds, including those who identify as culturally and linguistically diverse, and those from rural and remote areas also face a range of barriers to accessing appropriate health services. Major geographical barriers affect the ability of people to receive support, especially for those living in regional and remote areas of Australia. These barriers have a particularly significant effect on the large proportion of First Nations people living in remote and very remote areas.

In 2011, Australia committed to reforming disability services and established the National Disability Insurance Scheme (NDIS, see here for more details www.ndis.gov.au). The NDIS saw a significant improvement and increase in resources to disability services in Australia, shifting the focus to the needs of individuals and prioritising individual choice. The scheme uses a taxpayer-funded insurance model to provide individualised funding to provide eligible people with disability with reasonable and necessary supports. Individuals are assessed after application. If deemed eligible, an individual receives a plan with funding allocated for support for everyday activities (e.g., access to community), support to build independence and skills (e.g., job skills training), and capital supports (e.g., assistive technology). The NDIS can provide limited funding for some disability-

specific health supports if there is a direct link between the health support and the person's disability. These health-related supports can include equipment and consumables a person may need to help manage their health or a specific health condition (e.g., dysphagia or continence supports) or funding for support to go to health appointments. As part of the introduction of the NDIS, the Council of Australian Governments (COAG) agreed on principles to determine the responsibilities of the NDIS and other service systems. However, in practice, health and disability supports for people with intellectual disability remain largely siloed due to a lack of cross-sector capacity building and immature interdisciplinary models of practice.

Over recent years, Australians with intellectual disability have experienced growing levels of inclusion across many areas of life, but segregation still exists. Most students with intellectual disability attend mainstream schools and can access support where needed. Approximately 12% of students with disability attend a segregated 'special school', with the majority of these individuals experiencing severe disability (Australian Institute of Health and Welfare, 2022b). In terms of living situations, people with intellectual disability live in the community, often with family, with support, or independently. However, some individuals may not have any choice about their co-tenants as they live in group homes run by an accommodation provider. Some people work independently or with support in open employment, or in a segregated environment such as 'supported employment', where they are paid a reduced wage. Those outside the workforce access disability supports such as day programmes, organised activities, or individual supports. At times, particularly in regional and rural areas, services or activities are limited or transport may be costly or unavailable.

Most people with intellectual disability are eligible for a government payment or pension which also gives access to discounts for key everyday items such as medications, electricity, and public transport. Despite this, the payment is often less than an individual's day-to-day costs resulting in twice as many people with disability experiencing financial stress than those without disability (Australian Institute of Health and Welfare, 2022b).

People with intellectual disability experience many barriers to accessing healthcare in Australia. Health professionals do not always communicate directly with them and can wrongly attribute their health symptoms to their disability (Weise, Fisher, Whittle, & Trollor, 2018). Family members and support people play a critical role in facilitating access to healthcare for this group.

People with intellectual disability have been involved in systemic advocacy to advance the health

rights of people with intellectual disability in Australia. A recent example of this is a national campaign, 'End Deadly Disability Discrimination – Our Health Counts' (Inclusion Australia and Council for Intellectual Disability, 2019), by Inclusion Australia and the Council for Intellectual Disability which led to the Australian Government developing The National Roadmap for Improving the Health of People with Intellectual Disability ('The National Roadmap'; Department of Health and Aged Care, 2021).

AUSTRALIA'S HEALTHCARE SYSTEM: A BASIC OVERVIEW

Australians, including people with intellectual disability, are supported through a multifaceted healthcare system in both the public and private sectors, underpinned by a principle of universal access (Australian Government Department of Health and Aged Care, 2019). Responsibility for specific components of healthcare rests with the Federal and State/Territory Governments and is funded by a mixture of public and private sources. However, each of these governments has policy differences, which impact how health services are delivered. They also face the challenges of delivering equitable services across large land mass, and metropolitan, regional, rural, and remote settings.

Medicare is the Australian universal health insurance scheme funded by taxpayers and is the primary source of funding for public and a component of private out-of-hospital specialist health services. It provides capped reimbursement for out-of-hospital medical consultations, and free access to public hospital-based care including outpatient services. The Pharmaceutical Benefits Scheme provides public funding to substantially subsidise pharmaceutical costs (Australian Government Department of Health and Aged Care, 2023). Private health insurance can additionally be purchased by Australians to cover private hospital and some allied health services (Australian Government Department of Health and Aged Care, 2022). However, after reimbursement by the insurer, there are usually still some out-of-pocket expenses. Private health insurance is often inaccessible to low-income earners due to cost. Electronic health records are commonplace, with the government 'MyHealth Record' initiated in 2012 as an opt-out system containing key healthcare information on each Australian. However, the lack of interface between these record systems and the disability service sector plays a contributing factor to poor health information exchange.

The key elements of the Australian healthcare system include primary care, Aboriginal community-controlled health organisations, hospitals, and ancillary services.

Primary care

Primary care is often a person's first point of contact with the healthcare system and is provided by General Practitioners (GPs) and sometimes by Practice Nurses in privately owned community-based practices (Australian Institute of Health and Welfare, 2016). The use of telehealth by GPs has been spurred by the COVID-19 pandemic. In Australia, people can freely choose their GP, and can see more than one GP.

GPs play a key role in supporting people to navigate the healthcare system. A referral from a GP is required to access public hospital treatment, Medicare reimbursement for out-of-hospital private specialist services, including imaging and pathology, and for sessions with private psychologists and allied health professionals (Australian Government Services Australia 2023). GPs set their own fees for service which are often greater than the reimbursement available through Medicare. In this situation, the person is responsible for the fee gap; some GPs waive this fee gap for low-income earners (termed 'bulk billing').

Aboriginal community-controlled health organisations

Aboriginal community-controlled health organisations play an important role in delivering holistic, comprehensive, and culturally appropriate healthcare to the Aboriginal and Torres Strait Islander community who control it. These organisations came about due to the significant health gap experienced by Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare, 2022a) and the inability of mainstream services to effectively engage First Nations communities with their services. Aboriginal community-controlled health organisations provide services needed by the community and can include GP, maternity, and allied health services. Importantly, as a part of the way Aboriginal community-controlled health organisations provide a culturally centred and comprehensive approach to primary healthcare, they provide services to address social determinants of health (e.g., a school readiness programme for children, access to fresh produce through a food bank; Pearson et al., 2020). As they are controlled by the community, these services are designed to be flexible and responsive to community need.

Hospitals

Hospitals provide services to admitted patients, including urgent and elective care, and to non-admitted patients

through specialist outpatient clinics and emergency departments (Australian Institute of Health and Welfare, 2022c). Australians can access public or private hospitals. Public hospitals are co-funded by the Federal and State/Territory Governments and largely owned and managed by State/Territory Governments. Private hospitals are owned and managed by for-profit and not-for-profit organisations and operate on a fee for service basis, subsidised through a combination of Medicare and private health insurance payments (Australian Government Department of Health and Aged Care, 2022). Hospitals vary in location, size and the services provided. Major hospitals tend to be based in capital cities, which coupled with the geographical distribution of Australia means patients can be required to travel substantial distances to access these services. Specialist clinics, also known as outpatient clinics, are a common way to see a government-funded medical specialist and can, at times, have lengthy waitlists. Services in rural communities are supplemented by 'fly-in fly-out' health staff where necessary, and emergency services are supported by the Royal Flying Doctor Service who fly to regional, rural, and remote areas to provide care.

Community health services

Community health services are delivered by public hospital-based health networks and community mental health, drug and alcohol, sexual health services, child health services, and health promotion programmes like breast screening. Public dental services are also delivered through community health centres to those with a concession card but due to high demand often have long wait times. Some health and dental services screening programmes are provided in schools to improve access. Ancillary services are also provided in the private sector for a fee.

AUSTRALIA'S HEALTHCARE SYSTEM: RESPONDING TO THE NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITY

Australian healthcare policy

The healthcare needs of people with intellectual disability are very poorly recognised across the spectrum of healthcare policy from preventive healthcare to palliative care. The need to overcome this and to have consistent representation nationally is key recommendations from the Disability Royal Commission and the National Roadmap. A review of mental health policy found people with

TABLE 1 Healthcare policies reflecting good practice for people with intellectual disability.

Name	Region	Purpose	Strength
National Roadmap for Improving the Health of People with Intellectual Disability (2021)	National	Outline reforms to the health system to ensure it meets the needs of people with intellectual disability	A comprehensive and actionable list of objectives to meet over the next 10 years Produced with input from people with intellectual disability, their support people, clinicians, and researchers
Australia's Disability Strategy 2021–2031	National	Outline practical changes for an inclusive Australian society. Many actions for the health system but policy sits with disability system	Articulates the rights of people with intellectual disability to highest attainable standard of health. It also identifies the need for care across the spectrum and for both physical and mental health
Better Care Together – a plan for Queensland's state-funded mental health, alcohol and other drug services to 2027 (2022).	Queensland	Mental health plan for the state of Queensland which includes intellectual or developmental disability mental health for the first time	Emphasises the importance of improving provision of co-designed mental health services to people with intellectual or developmental disability. Has led to a commitment to fund capacity building activities in this area

intellectual disability are poorly represented with only 2 of the 37 documents reviewed including specific strategies or measurable targets to improve access to mental health services for those with intellectual disability experiencing mental illness (Dew et al., 2018). There are, however, some examples of good practice in healthcare policy which are summarised in Table 1. The strengths of these policies are they have often involved (or plan to involve) people with intellectual disability and their supporters in the design and delivery of the policy and aim to increase or improve access to services.

Healthcare system design

Australians with intellectual disability are expected to access mainstream health services (as described in [Australia's healthcare system: A basic overview](#) section), and that mainstream services will be able to adapt to meet their needs. However, without clear policy directives, mandated reasonable adjustments (positive adjustments that address access barriers), equipped healthcare workers, or specific additional funding, mainstream services have struggled to meet their needs. For example, additional funding may not be available to cover support to attend healthcare appointments. The system has also faced challenges in understanding and responding to need, because of the inability to accurately identify people with intellectual disability in medical records and routinely collected administrative health data sets.

Within primary care, health assessments for people with intellectual disability are encouraged through

incentivised additional funding via a specific Medicare item, introduced in 2007. Prior to 2010, this was a separate Medicare item which allowed for tracking of the number of assessments but has since been amalgamated into one item for health assessments alongside other vulnerable groups, making it impossible to track usage for people with intellectual disability.

Across Australia, there are several specialised government-funded intellectual disability health services (see Table 2 for some examples of specialised services); however, these services are usually small in relation to the population need, and generally do not offer ongoing follow-up and care. The specialised services all operate differently and are usually located in metropolitan areas, making it difficult for those in regional and remote areas to access them. A strength of some of these services is they work to build capacity of mainstream health services in intellectual disability healthcare through the provision of training and mentorship, as well as being involved in research. There are also a very small number of private specialist intellectual disability health services and health workers. However, for many individuals, these are difficult to access due to their small scale, increased financial costs, and location.

Healthcare workforce

The education available to health professionals in Australia falls short of what is required to help improve the poor health status of people with intellectual disability (Disability Royal Commission, 2022). For example,

TABLE 2 Examples of specialised intellectual disability healthcare.

Name	Service description	Service challenges
Mater Intellectual Disability and Autism Service, Queensland	State-wide outpatient service for individuals 16 years and over with intellectual or neurodevelopmental disability using a consultation-liaison model In-person appointments only at hospital in capital city, telehealth available for those outside area	No scope for travel Unable to provide follow up or ongoing care Based in a hospital but do not have admitting rights
Disability nurse navigators, Queensland	Senior advanced practice nurses who support complex patients with disability through the health system	Only available in select hospitals in wider capital city area
State-wide Intellectual disability health service, New South Wales	This service consists of six intellectual disability healthcare teams across NSW. The teams provide comprehensive health assessments and recommendations for people with unresolved or complex need that cannot be currently met by the service sector. The teams also deliver capacity building activities for health professionals in intellectual disability health	Need to be referred by a treating health professional
Specialist state-wide intellectual disability mental health Hubs, New South Wales.	Two Specialist state-wide intellectual disability mental health Hub services are operational in NSW. One is for children and younger persons and the other is for adults. The Hubs offer face-to-face support, virtual care, specialised assessment and case planning in mental health. The Hubs also provide education and training to health professionals in intellectual disability mental health	To be eligible for the service the person needs to have an ongoing care arrangement with referrer Unable to provide ongoing care
Mental Health Service for People with Intellectual Disability, Australian Capital Territory	A consultation-liaison service that provides assessment and treatment to people with a known or suspected intellectual disability and a known or suspected mental illness/disorder	Unable to provide ongoing care
Centre for Developmental Disability Health State-wide service, Victoria	Community based specialist team, consisting of mostly GPs, using a secondary consultation service whereby advice about assessment management is provided to the referring health professional. Also provides medical student training and professional development for health professionals	Unable to receive direct referrals to work with the person
South Australia Intellectual Disability Health Service (SAIDHS), South Australia	State-wide, specialised health service providing medical and mental health assessment and consultation for adults with intellectual disability and complex needs	Unable to provide ongoing care but can provide short term follow-up

Abbreviation: GPs, General Practitioners.

audits of intellectual disability content in medical and nursing curricula across Australian universities found intellectual disability content and teaching methods vary greatly between universities. These audits found only 10% of nursing schools, and 15% of medical schools offered substantial intellectual disability health content, and few universities offered direct clinical contact with people with intellectual disability (Trollor et al., 2020; Trollor, Eagleson, et al., 2016; Trollor, Eagleson, Turner, Salomon, et al., 2018; Trollor, Eagleson, Turner, Tracy, et al., 2018; Trollor, Ruffell, et al., 2016). Research also shows health professionals lack the capacity and confidence to meet the health needs of people with intellectual

disability (Weise & Trollor, 2018). People with intellectual disability and their support networks, in addition to clinical experts, have also identified the capabilities of the workforce to meet intellectual disability health needs are insufficient (Weise, Fisher, & Trollor, 2018; Weise, Fisher, Whittle, & Trollor, 2018).

There are, however, individual champions and professional and peak organisations across the different health and disability professional groups who have contributed extensively to equipping the sector in intellectual disability health. These individuals and groups have contributed and supported advocacy campaigns around intellectual disability health, made policy and parliamentary

submissions at state and national levels and facilitated professional development opportunities within their field. For example, organising and hosting roundtables to discuss intellectual disability health and mental health which produced national communiques, and ultimately, The National Roadmap (Department of Developmental Disability Neuropsychiatry, 2018; New South Wales Council for Intellectual Disability, 2013). Action has also occurred in the development and implementation of an intellectual disability mental health core capability framework that articulates core attributes required of the mental health workforce and provides a roadmap for professional development in the area (Department of Developmental Disability Neuropsychiatry, 2016). At a national level, the Department of Health and Aged Care has initiated curriculum development in intellectual disability health to support universities and accreditation authorities to improve pre-registration education for health professionals to meet the needs of people with intellectual disability (Australian Government Department of Health and Aged Care, 2023). The Royal Australian College of Physicians is also working to restructure their curriculum for trainees, in response to the findings from the Royal Commission.

Pandemic and disaster response

The COVID-19 pandemic and recent disasters in Australia demonstrated the lack of capacity, poor linkages between disability and health services and an unpreparedness to respond in a way that considers and supports the needs of people with intellectual disability. Early in the pandemic, government health messaging was inaccessible; it used jargon, was inconsistent in the use of language (e.g., social vs. physical distancing) and made messaging unnecessarily complex. Advocacy and disability organisations stepped up to create accessible information during this time and advocated to the Federal Government for a specific response to the needs of people with disability (Department of Developmental Disability Neuropsychiatry, 2020). In April 2020, the Federal Department of Health and Aged Care responded and launched the Management and Operational Plan for People with Intellectual Disability which aimed to ensure the rights under the UNCRPD were upheld during the pandemic (Australian Government Department of Health and Aged Care, 2021). A legacy of the pandemic is the improved collaboration between disability and health sector at Federal and State/Territory levels. Many of the learnings from the pandemic have been applied to disaster planning, a growing area of need in recent years. These learnings

include involving people with disability in planning, tailoring services to individual support needs and considering how people receive, give, and understand information. They have also been used to develop the Person-Centred Emergency Preparedness (P-CEP) Toolkit (Villeneuve et al., 2020).

AN EMERGING EVIDENCE BASE FOR HEALTHCARE FOR PEOPLE WITH INTELLECTUAL DISABILITY IN AUSTRALIA

This section summarises the key contributions from five papers to the evidence base for healthcare for people with intellectual disability in Australia (see Table 3). These papers were selected based on their contribution to policy and practice in intellectual disability healthcare in Australia. The intellectual disability health sector in Australia has strong roots in primary care, where a lot of early research and pivotal work around the utility of health assessments was undertaken (e.g., Lennox et al., 2010). More recent research has focused on understanding knowledge and skill gaps in our health workforce (e.g., Cashin et al., 2022) and describing how people with intellectual disability use our health system to inform service planning (e.g., Srasuebku et al., 2021).

DISCUSSION: REFLECTIONS ON BEST PRACTICE, KEY GAPS, AND FUTURE DEVELOPMENTS

Due to the efforts of people with intellectual disability, support people, advocates, clinicians, and researchers, intellectual disability health has received growing attention in Australia. Importantly, as a nation, we currently have a commitment from both Federal and State/Territory Governments to make a change. At a national level, the impact of the Disability Royal Commission and The National Roadmap cannot be underestimated. The Royal Commission will hand down its findings in late 2023 and could be a further catalyst for change. Funding and resource commitment from The National Roadmap is continuing. Moving forward, it is imperative that people with intellectual disability are recognised as a priority population by National Cabinet, and the field continues to work together to avoid creating a disjointed area with duplication. There are three key focus areas for future developments: improved implementation of health assessments, capacity building of the health workforce, and development of improved evidence-based models of care.

**TABLE 3** Key intellectual disability healthcare contributions.

Area	Reference	Brief overview	Key contribution
Primary Care	Lennox et al. (2010)	Cluster randomised-controlled trial of a health assessment with adults with intellectual disability	Demonstrated increased health promotion, disease prevention and case-finding activity in adults with intellectual disability who had completed a health assessment using the Comprehensive Health Assessment Program (CHAP) Directly contributed to the addition of a Medicare item for health assessments
	Weise et al. (2017)	Secondary analysis of Bettering the Evaluation and Care of Health programme to compare primary care encounters for people with and without intellectual disability	Demonstrated primary care for people with intellectual disability is dominated by administrative instead of medically related actions. This study also highlighted the under management of common health problems for people with intellectual disability. People with intellectual disability also had more indirect encounters with the GP and longer consultations, with more problems managed per appointment compared with people without intellectual disability. This research highlighted additional support required in primary care to meet the needs for this group. It was used as evidence in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
Healthcare workforce	Cashin et al. (2022)	Survey of nurses to understand preparedness, knowledge, comfort, and confidence of Australian Registered Nurses in caring for people with intellectual disability and autism	Demonstrate nurses working in mainstream government services reported low levels of self-reported knowledge and confidence working with patients with intellectual disability. Analysis identified areas of educational and confidence building training (e.g., skill development around communication, referral pathways) needed for nurses in different practice contexts (e.g., acute hospital, community, emergency)
Health service system	Srasuebkul et al. (2021)	Retrospective cohort data linkage analysis of people with and without intellectual disability using publicly funded inpatient and community mental health services in NSW	Demonstrated people with intellectual disability use public mental health service more than people without intellectual disability. Annual costs for people with intellectual disability are estimated to be \$30 418 compared with \$11 727 for those without intellectual disability. This study was used as evidence to advocate for equipping the mental health sector in the area of intellectual disability mental health
	Trollor et al. (2017)	Retrospective cohort data linkage analysis of people with and without intellectual disability investigating mortality	This study found Australians with intellectual disability have premature mortality and an over representation of potentially avoidable deaths (38% of deaths for people with intellectual

TABLE 3 (Continued)

Area	Reference	Brief overview	Key contribution
			disability compared with 17% for comparison cohort). Used as evidence in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and one of the key drivers for the development of The National Roadmap

Groundwork, including Medicare reimbursement and collation of evidence of effectiveness, has been laid to support routine application of comprehensive annual health assessments by GPs. However, anecdotal evidence suggests the quality and quantity of health assessments is declining (Disability Royal Commission, 2020). Further advocacy and action are required to reinstate a separate Medicare item for these health assessments, to enable population-level data to be examined, and to explore how to best support their successful implementation in primary care. Current projects in this space, stemming from the National Roadmap, include work to investigate how general practice nurses may be supported to play a larger role in the delivery of a health assessment, how to incorporate a health assessment in practice software, and embed health assessments in quality improvement activities for practices.

Australia's health and disability workforce requires urgent equipping to enable professionals to better support access to quality healthcare for people with intellectual disability. There are five critical goals in this space. First, Australia needs to improve training provided to future health professionals; this is a key stage where we can shape attitudes and teach skills around intellectual disability. Second, to mitigate the lack of training, skills, and confidence when working with people with intellectual disability, mandatory training for our current health workforce is needed to ensure minimum skills (e.g., making reasonable adjustments, communication). A targeted approach is also needed including training for staff working in specific 'high use' departments, such as emergency and inpatient settings, and for those within relevant medical specialities, such as general practice, psychiatry, general medicine, and emergency medicine. Finally, the need to increase subspecialty training in key medical specialities like psychiatry, general practice, general physician, and rehabilitation will increase workforce capacity. Currently, individual champions have been pivotal in gaining access to local services and universities to deliver education and build capacity of health professionals. Likewise, there are numerous initiatives from specialist

intellectual disability health teams and peak organisations across the different health professional groups who have contributed extensively to addressing these goals. Bringing this all together, The National Roadmap is working on developing the Intellectual Disability Health Capability Framework which will set out clear capabilities and bring together resources to support the teaching of intellectual disability healthcare (Australian Government Department of Health and Aged Care, 2022).

The development of evidence-based models of care is integral to ensure equitable access to health services for people with intellectual disability and those who support them. Such models must be person-centred, consider disability supports, and integrate with the disability system. Models must also ensure decision-making is shared between health professionals and people with intellectual disability (and, where appropriate, their support people), and facilitate reasonable adjustments in response to people's needs. In a good first step, The National Roadmap supports the need to develop better models of care, build the capacity of health professionals, develop a guide to making reasonable adjustments, and explore avenues to incorporate into models of care.

CONCLUSION

Intellectual disability healthcare is at a dynamic point in Australia. Federal and some State/Territory Governments have made financial and service commitments to improve access to healthcare and ultimately health outcomes. It is imperative that advocates with intellectual disability, support people, researchers, and clinicians, continue to work together to ensure this momentum from policy to practice continues and makes a real difference to the health experiences and health outcomes of Australians with intellectual disability.

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CONFLICT OF INTEREST STATEMENT

No conflict of interests to declare.

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ORIGINAL ARTICLE



Ireland's approach to health and social care policy and practice for people with intellectual and developmental disabilities

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Abstract

Irish health and social care policy has undergone a significant evolution in recent years to address inequalities, improve standards and update models of care to incorporate a rights-based approach. The following account describes the Irish health and social care system, as delivered in the Republic of Ireland, and details how it operates for those with intellectual and developmental disabilities. The paper is informed by government policy, legislation, reviews, national plans, parliamentary reports, and population data. Clear progress has been made in shifting from a service-led to a rights-based, service-user led model of care; however, resourcing this fundamental transition in approach to service provision poses challenges for the Irish State.

KEYWORDS

developmental disability, health services, intellectual disability, Ireland, policy, practice

IRELAND'S POPULATION AND GENERAL HEALTHCARE SYSTEM

In terms of the numbers the Irish healthcare system must serve, Ireland's overall population has exceeded 5 million people for the first time since 1851; findings of the 2022 national census revealed a figure of 5 149 139 (51% female) residents, which is an 8% increase from the 2016 census (Central Statistics Office, 2023). A total of 1 109 557 people, accounting for 22% of the population, reported experiencing at least one long-lasting condition

or difficulty to any extent. Of these, 407 342 people (8% of the population) reported experiencing at least one long-lasting condition or difficulty to a great extent or a lot and 702 215 people (14% of the population) reported experiencing a long-lasting condition or difficulty to some extent or a little (Central Statistics Office, 2023). In 2022, 73 927 people (36% female) were recorded as receiving or requiring disability funded services as a result of an intellectual disability; developmental delay; physical, sensory, neurological, learning, speech and/or language disabilities; or autism (Health Research Board, 2023).

General health policy in Ireland is led by the Government's Department of Health (DoH). It directs policy and governance and oversees the health sector's performance and organisational structure (DoH, 2021a). In March 2023, responsibility for specialist community-based disability services, including management of the disability health budget, transferred from the Department of

Abbreviations: CDNTs, Children's Disability Network Teams; GPs, general-practitioner doctors; HIQA, Health Information and Quality Authority; HSE, Health Service Executive; IDD, intellectual and developmental disabilities; MDTs, multidisciplinary teams; NASS, National Ability Support System; NDIS, National Disability Inclusion Strategy 2017–2021; UNCPRD, The United Nations Convention on the Rights of Persons with Disability.

Health to the Department of Children, Equality, Disability, Integration and Youth (DCEDIY, 2023).

More specifically regarding service delivery, meeting Ireland's health and social care needs is the responsibility of the Health Service Executive (HSE), a single independent government agency reporting to the Department of Health and now also the Department of Children, Equality, Disability, Integration and Youth. The HSE was established under the Health Act (2004), replacing the previous system of regional Health Boards. In terms of health services, the HSE is tasked with improving, promoting, and protecting the health and welfare of the public, which it does through managing and delivering, or arranging to be delivered on its behalf, health and personal social services. Under the Sláintecare reform programme, described later, the HSE is moving away from a model based on separate streams such as acute hospitals, primary care, and mental health, to an integrated care model delivered through six regional health authorities (DoH, 2022). The HSE's disability function is managed jointly by a central team, and by local disability managers in each of the regional units.

Services are delivered directly via HSE owned and governed services, through voluntary organisations or private services (HSE, 2021a), and comprise a diverse range of organisations across the country, from hospitals to religious orders and non-profit organisations, but are generally closely integrated with services provided directly by the HSE (DoH, 2019). Similar to other European countries, the voluntary sector plays a substantial role in general healthcare delivery in Ireland. For example, approximately one third of acute in-patient hospital beds are provided through voluntary hospitals (DoH, 2019). This is particularly the case for disability services where almost 70% of services are provided through voluntary organisations funded under the Health Act 2004, approximately 27% are provided directly by the HSE with the remaining 4% provided through private sector bodies (DoH, 2021b).

In terms of financing healthcare, the Government allocates funding annually to operate the health and social care system. The HSE receives more funding than any other State body and is the State's largest employer. In 2023, €21.6 billion was allocated to the HSE (HSE, 2023), of which approximately €2.6 billion is allocated to disability services (Government of Ireland, 2023), which is considered to be insufficient to meet current and future needs (Oireachtas, 2022). The Value for Money and Policy Review of Disability Services completed in 2012 recommended changing from an approach that was predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports. Following a 2018 Task Force on

Personal Budgets, different options of personal budgets in lieu of direct service provision are being piloted over the 2020–2023 period (DoH, 2018).

Historically, Ireland has had a tiered system of eligibility for free healthcare (full eligibility or limited eligibility). Everyone ordinarily resident in Ireland is entitled to a range of public health services either free of charge or at reduced cost, including free or subsidised care as a public hospital patient. Those on lowest incomes may qualify for a full medical card, which covers the following free of charge: general-practitioner doctors' (GPs) services, prescribed drugs and medicines (subject to a prescription charge), public hospital services, community care and personal social services, specific dental, optical and aural services, and maternity and infant care services (Citizensinformation.ie, 2022a, 2022b; HSE, 2021a). Most people with an intellectual disability will qualify, on income grounds, for a medical card. Under the Sláintecare reform programme, the intention is to move progressively towards universal healthcare, free at the point of use. State-funded disability support services are provided free of charge; however, people living in a residential care service may be required to pay towards the cost of their accommodation and living (DoH, 2018).

Despite the appearance of universal public healthcare, variations in coverage, access and cost across the country led to a two-tier system, exacerbated by the 2008 economic crisis, where those who could afford it paid for services directly or through private insurance, leaving those on lower incomes and people entitled to full eligibility, encompassing a significant proportion of those with disabilities, subject to lengthy waiting times for diagnosis and treatment. This prompted the government to commence a 10-year systemic reform of State healthcare provision in 2018 through the policy Sláintecare (Oireachtas Committee on the Future of Healthcare, 2017).

Sláintecare entails moving to a population-based planning approach to healthcare, based on demographic and geographic considerations, to reflect the health and social care needs of all citizens, including people with intellectual and developmental disabilities (IDD). Sláintecare aims to address inequities in the system by ensuring timely universal services are delivered close to where people live based on clinical need, with emphases on prevention and community and social care services that support people to live independently in their homes for as long as possible. The stated goal of Sláintecare is to provide the right care, in the right place, and at the right time (Government of Ireland, 2021). While progress has been made, concerns over recruitment, cost and delays with implementation are reported (Lynch, 2022).

HISTORICAL SERVICE PROVISION AND POLICY FOR PEOPLE WITH IDD

Ireland became politically autonomous in 1922. At the time, limited resources and a strong relationship between the State and Catholic Church led to religious orders dominating health and social care service provision with little State oversight (Linehan et al., 2014). For the next four decades, religious orders were the preferred option for delivering services for people with IDD, whether healthcare or otherwise, partially financed through capital and land grants from the Irish State. Accountability for quality of care was confined to the governance structures of the religious orders, leading to variability in quality of services and little transparency (Barrington, 1987). Specialist residential services expanded in the 1930s with both children and adults, who previously received generic supports, being transferred to these facilities.

In the 1950s, as demand exceeded capacity of religious staff, the disability workforce expanded to include nursing and other professionals. Specialisms in IDD began to develop including in psychology, speech and language therapy, and occupational therapy. This period also saw the founding of voluntary services by parents' and friends' associations to expand the very limited number of specialist IDD services available, and to provide an alternative model to institutional care. An important shift in policy followed, initiated by the Commission of Inquiry into Mental Handicap in 1965, which acknowledged superior quality outcomes for people living in community care models compared to those in institutional settings (DoH, 1965). It recommended to Government that voluntary bodies should continue to provide services, but the State should accept responsibility for coordinating their activities. This led to the expansion of voluntary services, placing them at the centre of service provision where they remain to the present day. The legacy of the development of disability services outside of State planning and control has had consequences. For example, until recently, for people with IDD unlike for others in the general population, support and health services were interlinked within these specialist disability organisations. In addition, the geographical distribution of services has been uneven, meaning that individuals with IDD have been left without services in certain areas or have been compelled to move to group residences far from family support.

In 1990, in its first disability-specific policy report, Needs and Abilities (Government of Ireland, 1990), the Government further emphasised the importance of transferring disability support from group residential centres

to community-based living and acknowledged its role in promoting and monitoring standards across the different voluntary organisations. This report also acknowledged that people with disabilities were the neglected citizens of Ireland, suffering intolerable conditions owing to outdated social and economic policies and attitudes.

THE IMPACT OF THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITY (UNCRPD, 2006)

Ireland signed the UNCRPD in 2007, ratified it in 2018, and submitted its first State Report to the UN Committee in November 2021. Despite the delay in ratification, the UNCRPD significantly impacted policy development in that intervening period including through the policies 'Time to Move On' (HSE, 2011), which recommended the closure of congregated settings and proposed a new model of community support; 'New Directions' (HSE, 2012); and the Value for Money and Policy Review of Disability Services (DoH, 2012). These policies were underpinned by values of inclusion, person-centeredness, participation, community integration, independence, and choice in the knowledge that services would need to improve if they were to be UNCRPD-compliant (Linehan et al., 2014). In meeting its obligations, the Irish Government has collaborated with disability stakeholders to develop two policy strategies: the Comprehensive Employment Strategy for People with Disabilities 2015–2024 to improve access to employment and the National Disability Inclusion Strategy 2017–2021 (NDIS) to address equality factors related to public services for people with disabilities. The role of the National Disability Authority as an independent body responsible for advising on and monitoring compliance with the NDIS enhances its effectiveness. More recently, the Assisted Decision Making (Capacity) Act 2015 and Assisted Decision-Making (Capacity) (Amendment) Act 2022 were commenced, which established a new legal framework to support people with disabilities to exercise their autonomy in decisions to the greatest extent possible. Although it intends to do so, Ireland has not yet ratified the Optional Protocol, which provides a mechanism of complaint to the UN Committee for rights violations, with knock-on delays in the provision of further rights for people with disabilities (Joint Committee on Disability Matters, 2023). Table 1 sets out the key pieces of domestic legislation in Ireland that are relevant to disability services and shows the progress made in improving standards of care for people with disability.

TABLE 1 Irish legislation relevant to people with disabilities.

Prohibits discrimination and promotes equality in employment, ensuring that people with disabilities have equal access to employment, job progression and training	Employment Equality Acts 1998 to 2015
Establishes independent body (National Disability Authority) to provide evidence-based advice and research to Government on disability policy and practice	National Disability Authority Act 1999
Prohibits discrimination in relation to provision of goods, services, accommodation and education	Equal Status Acts 2000 to 2015
Provides for the regulation of, and involuntary admission to, approved centres for persons suffering from mental illness, severe dementia or significant intellectual disability	Mental Health Act 2001
Creation of central organisation (Health Service Executive) to deliver health services replacing regional health boards (not disability specific but initiated drive towards greater accountability and equality across all healthcare services)	Health Act 2004
Provides for equal rights to education for people with additional educational needs in an inclusive environment. It primarily focuses on children but also provides for review of higher and continuing education for adults as well as rehabilitation and training	Education of Persons with Special Education Needs Act 2004
- Establishes right to independent assessment of health and educational needs (Assessment of Need) for people with disabilities and subsequent service statement giving right to necessary services - Places statutory obligation on public service providers to support access to services, facilities, public buildings, and public sector employment for people with disabilities - Establishes right to independent complaints and appeals procedures	Disability Act 2005
- Establishes independent agency (Health Information and Quality Authority) to develop standards, inspect, and review health and social care services including residential centres for people with disabilities, reporting to Minister for Health - Amendment in 2013 defines and regulates use of restrictive procedures in designated centres	Health Act 2007
Development of personal advocacy service for people with disabilities (National Advocacy Service established in 2011)	Citizens Information Act 2007
Establishes the Irish Human Rights and Equality Commission to protect and promote human rights and equality, review Irish law and practice and consult with international bodies in this regard	Irish Human Rights and Equality Commission Act 2014
Replaces previous ward of court system with three-tiered system and Decision Support Service to support decision-making of adults with impaired capacity to different degrees. Strengthens functional test of capacity that is time and decision specific by giving it statutory basis	Assisted Decision Making (Capacity) Act 2015 Assisted Decision-Making (Capacity) (Amendment) Act 2022
Replaces blanket prohibition on people with IDD having a sexual relationship with consideration of capacity to consent	Criminal Law (Sexual Offences) Act 2017
Irish legislation giving effect to European Union Web Accessibility Directive which obliges public bodies to make websites and mobile applications accessible to all	European Union (Accessibility of Websites and Applications of Public Sector Bodies) Regulations 2020

CURRENT HEALTH SERVICE PROVISION FOR PEOPLE WITH IDD

In principle, people with IDD are entitled to general health services on an equal basis with all citizens,

although barriers to access exist (Joint Committee on Disability Matters, 2023). For acute care, access to hospital services is similar to the general population, typically occurring via GP referral and/or attending Accident and Emergency Departments (Citizensinformation.ie, 2023).

Access to GPs is typically in line with the general population where children and adults access community-based practices. Larger residential settings may employ or contract medical practitioners offering general practice although which GP the person accesses should remain their choice (Health Information and Quality Authority [HIQA], 2013).

Historically, access to community-based health and social care professionals at both primary and secondary care levels was through specific disability services and was therefore available only to people registered with the particular service, leading to unequal service provision. In line with Sláintecare, specialist mental health services for people with IDD are progressing towards a catchment and needs-based model. There has also been significant change in therapeutic service for children and young people up to 18 years with a disability or developmental delay, guided by the Progressing Disability Services for Children and Young People Programme (HSE, 2009, 2020), which recommended children's specialist disability services move to a catchment and needs-based model. Under this programme, teams of health and social care professionals have been created, termed Children's Disability Network Teams (CDNTs), who provide services to all children with complex needs within a defined geographical area. This has involved pooling together all resources, including equipment, facilities, and staff, from the HSE and voluntary agencies to set up these CDNTs. While it is envisioned that the programme, when fully rolled out, will provide national cover and equitable access for children based on need rather than diagnosis, there have been significant challenges with the rollout of the model, especially recruitment, resulting in lengthy waiting lists and difficulties with communication and service quality (Joint Committee on Disability Matters, 2023). Concerns regarding clinical risk due to the absence of clinical governance, clinical specialists, and scope of practice have also been highlighted (Irish Association of Speech and Language Therapists, 2022).

While adults with IDD may ostensibly access multidisciplinary therapies via primary care services, here they also experience greater barriers than the general population (DoH, 2021b), especially for those living in congregated settings or community-based group homes (National Federation of Voluntary Service Providers, 2019). Instead, access to some health and social care professionals continues to be provided through specialist disability teams attached to particular services, accessible to the services' defined client groups (DoH, 2021b). Newer catchment based multidisciplinary teams (MDTs) have been created; for example, the Young Adults Disability Teams, which support people transitioning from child to adult disability services. How these teams fit with existing

teams in services is not yet clear, highlighting the need for a full consideration as to how multidisciplinary supports will be structured in the future, so that people using services are not dependent on one entity for all their support but still benefit from strong connections between clinical and operational settings. The demand for therapy services for adults with IDD far exceeds current capacity and it is estimated that therapy services for people with IDD will need to increase by 71% by 2032 (DoH, 2021b).

In terms of specialist services, a number of secondary level services are being developed. Within mental health, specialist mental health teams for adults (Mental Health Intellectual Disability) and children (Child and Adolescent Mental Health Service in Intellectual Disability) with intellectual disabilities in the 'moderate' range or below are being developed in line with their respective national models of service towards catchment-based services (HSE, 2021b, 2022). These models of service outline the vision, strategic direction and resource requirements for implementation, and provide guidance on service delivery and integration with existing mental health, disability and primary care services. A national IDD dementia service has also been developed, accessed through GP referral, which offers baseline screening and diagnostic assessment as well as post-diagnostic support.

CURRENT SUPPORT SERVICE PROVISION FOR PEOPLE WITH IDD

Specialist community-based disability support services include supported housing, respite services, assistive technology, support for community engagement, and day services (DoH, 2021b). A national database (National Ability Support System, NASS) of the HSE-funded disability services received or required by people with neurological and neurodevelopmental disabilities reports 73 927 registered service users for 2022, of whom 45 068 (30% female) are accessing children's services, and 28 859 (46% female) are accessing adult services, which it acknowledges is based on incomplete data. For children, autism was reported as the primary disability (39%), followed by intellectual (24%), physical (6%), and neurological (2.9%) disability. For adults, intellectual disability was reported as the primary disability (63%), followed by neurological (17%), physical (7%), and autism (5%) (Health Research Board, 2023). The breakdown in IDD severity for adults was 32% (mild), 47% (moderate), 15% (severe), and 4% (profound). Currently, the majority of people with IDD live in their family home with parents. However, in residential settings, people with IDD represent about 90% of all people with disabilities in the



approximately 8100 residential care placements (Department of Housing, Local Government, & Heritage, 2022). In 2022, 7486 children and adults lived in a residential setting, 3516 children and adults received home support, 3196 children and adults accessed overnight respite, and 18 183 adults accessed day services (Health Research Board, 2023). The number of adults requiring these services is expected to increase by 10% in 2027 and as much as 17% by 2032 (Government of Ireland, 2023).

New residential places are developed largely in line with current policy, which recommends that people with disabilities should be supported to live in dispersed housing in the community with individualised supports designed to meet their needs and wishes, including the choice to live alone or with others, to a maximum of four persons with disabilities (HSE, 2011). However, facilitating such choices is not always possible as it is resource dependent. Despite the progress made to transition people living in older institutionalised settings to newer models of support and closing new admissions, approximately 2000 people were still living in congregated settings in 2021 (Oireachtas, 2021).

While there have been significant developments in policy, access to residential places has fallen since 2008, leaving an estimated shortfall of up to 2300 places (DoH, 2021b). There are a minimum of 800 people with disabilities on the HSE's Emergency/Urgent waiting list and the Government estimates that between 1900 and 3900 extra residential places will be needed by 2032 to address both unmet needs and demographic change (DoH, 2021b). Furthermore, without access to appropriate housing supports, the move towards community integration, proposed to increase independence, has led to families assuming increasing residential responsibility for people with IDD (Brennan et al., 2022). Given the significant waitlists, access to new residential placements generally occurs in unplanned emergency situations, such as the death of a caregiver. A majority of these emergency placements have been provided in the for-profit sector (Oireachtas, 2022).

People living at home can access respite in the form of overnight breaks, extended day service, or clubs/activities (DoH, 2021b). Alternative forms of respite, such as in-home respite, are being developed and some organisations offer respite in the form of home-sharing with vetted families. Respite services are primarily intended to support family carers and to provide a good experience for the person with IDD (DoH, 2021b). Recent investments in respite services proved insufficient to meet the level of need. This is compounded by an increase in people with IDD living at home requiring respite and the longer-term use of respite for people in crisis who are

unable to access a permanent residential placement. In 2017, less than a quarter of children with IDD and only a third of adults living at home with their family received HSE-funded respite activities (DoH, 2021b).

The Health Information and Quality Authority (HIQA), established under the Health Act (2007), has statutory responsibility for setting and monitoring compliance with standards in the quality of health and social care. Its remit includes nursing homes, and residential and respite homes for adults and children with disabilities. A review of the first 5 years of regulation found gradual improvement in compliance, with poor governance directly linked to people's lived experience (HIQA, 2019). For both residential and respite services, while HIQA regulation has improved the quality of service delivery, it has reduced available places. This is due to the imposition of certain rules that improve living standards but necessarily reduce capacity; for example, sharing bedrooms and using temporarily vacated beds in a residential home for respite are no longer permitted. The Mental Health Commission similarly regulates approved in-patient mental health services, including those for people with IDD.

To live as independently as possible, people with disabilities can seek support from personal assistants, home help, community support services, and assistive technology. Approximately 2500 people receive support from personal assistants, averaging 12 hours per week, and approximately 8000 people receive home-support hours, averaging 7 hours per week (DoH, 2021b). These services are largely directed to assist people with physical or sensory disabilities; people with IDD account for just a quarter of home-support recipients, half of whom are children. Data quantifying the level of unmet need is lacking but the level of support available is considered to be only a fraction of what is required, with friends and family filling the gap where possible (DoH, 2021b). This is highlighted by the NASS data from 2022: 62% of respondents not living in a residential setting had a primary informal carer, of whom the vast majority were parents.

Historically, day services mainly involved segregated community workshops offering activities, vocational training, and sheltered work (HSE, n.d.). A review of day services initiated in 2007 found an absence of defined service activities or nationally agreed standards for day services, leading to a lack of consistency in their design and provision (HSE, 2012). This review led to a change agenda to implement a new vision and guidelines for day services, termed 'New Directions'. This model, developed by the HSE, espouses a community-based and outcome-focused approach based on individualised planning, guided by standards and defined supports that should be

TABLE 2 Recent popular and scientific publications related to health and service provision for people with IDD in Ireland.

Reference	Type	Topic reference
Doyle, A., O'Sullivan, M., Craig, S., & McConkey, R. (2021). People with intellectual disability in Ireland are still dying young. <i>Journal of Applied Research in Intellectual Disabilities</i> , 34, 1057–1065	Peer reviewed article	Compares mortality rates for people with intellectual disabilities with the general population in Ireland
Doyle, A., O'Sullivan, M., Craig, S., & McConkey, R. (2022). Predictors of access to healthcare professionals for people with intellectual disability in Ireland. <i>Journal of Intellectual Disabilities</i> , 26, 3–17	Peer reviewed article	Outline access to healthcare professionals for people with intellectual disabilities
Joint committee on Disability Matters. (2023). <i>Aligning Disability Services with the United Nations Convention on the Rights of Persons with Disabilities</i> . Dublin: Tithe on Oireachtais	Government report	Reviews current disability services with UNCRPD
Murphy, K., & Bantry-White, E. (2021). Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. <i>Disability & Society</i> , 36, 750–771	Peer reviewed article	Examines human rights in residential care using Irish residential inspection reports
Trinity Centre for Ageing and Intellectual Disability's IDS-TILDA Suite of Reports: IDS-TILDA Wave 1—Growing Older with an Intellectual Disability in Ireland IDS-TILDA Wave 2—Advancing Years, Different Challenges IDS-TILDA Wave 3—Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland IDS-TILDA Wave 4—The Impact of COVID-19 on People Ageing with and Intellectual Disability in Ireland Available from: https://www.tcd.ie/tcaid/research/publications/reports.php	Research reports	Reports of longitudinal study researching ageing in Ireland among people with intellectual disabilities aged 40 and over

available to all people accessing day services, supporting people to live a life in accordance with their own choices, needs, and aspirations (HSE, 2015). The voluntary sector provides the majority of HSE-funded day services, which can be community-based or in-situ in residential settings, at approximately 1000 locations (DoH, 2021b). Standard programmes are 5 days a week but can be shorter due to funding deficits. Participation is generally lifelong. Consequently, demand from new applicants significantly exceeds vacancies arising; since 2015, approximately 1000 additional day places have been required each year (DoH, 2021b).

PROGRESS REVIEW

Despite these advances in policy, a recent review on how disability services, especially health, is aligning with the UNCRPD noted significant deficits (Joint Committee on Disability Matters, 2023). These include segregation and inaccessible mainstream health services, a continuing medical model approach in services for people with more

complex disabilities, delays in developing and implementing policies and legislation to enable progress, such as decongregation and group-based funding models, lack of intervention, and a lack of public awareness of these difficulties. To counter these, it notes priority recommendations including integrating disability into Sláintecare, reforming legislation to align with the UNCRPD, working to recruit and retain staff, and funding services appropriately. This report, along with recent popular and scientific publications useful to understanding service provision for people with disabilities in Ireland, is listed in Table 2.

DISCUSSION

Since the foundation of the Irish State and before, the structure of services for people with IDD was strongly influenced by a combination of scant resources and a strong, and dependent, relationship with religious orders. Its legacy is the ongoing State provision of health and social care predominantly through voluntary disability agencies. In line with national policy and the UNCRPD,



disability services are becoming more person-centred, community-based, and rooted in a human rights approach, underpinned by regulations and standards governing residential disability services. While general services are theoretically available to all, barriers exist in practice. Some areas of health and social care have progressed further than others in terms of reform of models of care. However, in some instances, regulations aimed at raising quality have had a side effect of reducing availability of services, such as residential places, and transitioning to catchment based models has widened access to services at a time when factors impacting service delivery, including recruitment and retention, pose significant challenges. Moreover, current unmet needs, demographic changes, and an estimate that current disability spending would need to increase by between a quarter and a half to deliver the required capacity means demand exceeds services on all governmentally reviewed indicators (DoH, 2021b). This has resulted in lengthy waiting lists, continued unmet needs, and the necessity for families and friends to bridge service gaps. Overall, the shift in ideology underpinning the structure of services from a charitable to a rights-based, person-centred model, which emphasises community integration, has led to progress in moving from a service-led to service-user led model of care, with the contextually progressive, but ultimately modest, principle of supporting people with disabilities to live ordinary lives in ordinary places. However, reforming systems alone will not achieve this without the appropriate resources, and so the provision of health and social care for people with disabilities continues to be contingent on the allocation of the Irish State's resources.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

ETHICS STATEMENT

As this is a description of the healthcare system in Ireland, it did not involve recruitment of participants or an experimental design and therefore ethical approval and consent were not required.

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Health care for people with intellectual disability in Spain

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Abstract

We describe the healthcare system for people with intellectual disability (ID) in Spain. First, we provide general population statistics before focusing on the most recent prevalence data related to people with disability in general, and with ID in particular. We also discuss how health care is organized. Most of the Spanish population is covered by the public healthcare system, which is structured into primary care (first-level health services; easily accessible and capable of tackling the most common ailments) and specialized care (second-level health services; comprising the most complex and costly diagnostic and therapeutic resources). We then explain Spain's primary legislation that promotes the rights of people with disabilities, highlighting the importance of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which is enshrined in the Spanish General Law on the Rights of People with Disabilities and their Social Inclusion (Royal Legislative Decree 1/2013). Second, we describe the organization of Spanish disability support and health services, whose regulation is highly complex given that the autonomous regions set their own rules about coverage, services, and financing. Third, we present some recent studies that allow a better understanding of health care for people with ID in Spain, including a summary of the ongoing #Rights4MeToo project. We report specific data on the right to habilitation/rehabilitation. People with ID and professionals providing them with supports agreed that the most problematic aspects of health care for people with ID were the lack of: coordination across services, user-friendly information to maintain or improve their health, psychological treatments, preventive medical check-ups, and knowledge about disability among health professionals. There is a need to give people with ID priority access to services, reduce waiting times, increase the length of medical appointments, and create protocols and prevention campaigns targeting them.

Abbreviations: ID, Intellectual disability; CRPD, United Nations Convention on the Rights of Persons with Disabilities; SNHS, Spanish National Health System; CERMI, Comité Español de Representantes de Personas con Discapacidad (Spanish Committee of Representatives of Persons with Disabilities).

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KEYWORDS

Convention on the Rights of Persons with Disabilities, health, health care, intellectual disability, mental health

INTRODUCTION TO THE GENERAL HEALTHCARE SYSTEM

General population statistics

Statistics from the Spanish Ministry of Health (2022a) indicate that Spain has approximately 47 million inhabitants, of whom 19% are over 65 years of age. Life expectancy is around 83 years, and 72 of these years are expected to be lived in a healthy way for the general population. The main causes of death in Spain are similar to those in countries with comparable socioeconomic environments: cardiovascular diseases, stroke, and cancer. According to a 2020 macro-survey on disability in Spain (National Institute of Statistics, 2022), 4.38 million people (9.5%) residing in households stated they had a disability. Mobility problems are the most frequent type of disability reported.

Although almost 10% have limitations and state they have a disability, in Spain only those who have been recognized with a degree of disability equal to or greater than 33% are legally recognized as persons with disabilities. Disability recognition is an essential prerequisite to have access to the social safety net (e.g., protected employment, financial support for studies, adaptations at home). The assessment and recognition of a disability is a long and decentralized administrative procedure carried out by a specialized team (made up of a doctor, a psychologist, and a social worker) that, upon request, establishes the diagnosis, evaluates the disability, and assesses the degree thereof. If the team assesses the degree of disability to be equal to or greater than 33%, then the person is legally considered as a person with a disability. People who met these criteria and therefore were considered as persons with a disability accounted for 7% of the population in 2020, and those who had intellectual disability (ID) as the main cause of their disability accounted for 0.6% (Institute for Older Persons and Social Services, 2022).

Among people with ID in Spain, the pyramid of the population by age is distributed as follows (Institute for Older Persons and Social Services, 2022): 3% were under 7 years old, 15% were between 7 and 17, 28% between 18 and 34, 45% between 35 and 64, 7% between 65 and 79, and 2% were 80 years or older. Most of them were living in the regions of Andalusia (23%), Catalonia (17%), Community of Madrid (12%), and Community of Valencia (9%). It is noteworthy that the rate of people with a recognized degree of disability with ID as the main cause fell by 0.2% between 2019 and 2020.

Beyond those with a legally recognized disability, the availability of data is highly insufficient as no existing sources provide comprehensive and updated information about the number and characteristics of people with ID and their care service use (Salvador-Carulla & García-Gutiérrez, 2009). Plena inclusión (2023) estimates that ID affects 1% of the Spanish population, taking into account that some people may not know that they have ID, and others have a diagnosis of ID but not a legally recognized disability.

Organization of the healthcare system

The healthcare system in Spain is both public and private. Private health care usually requires medical insurance and plays an important role in provision, especially for those people and treatments not eligible to be treated by the public system. Although there is a growing reliance on the private sector, most of the Spanish population is covered by the public healthcare system. Article 43 of the Spanish Constitution establishes the right to health protection and health care for all citizens. The Royal Decree-Law 7/2018 guarantees the universality of assistance and the right to health protection and health care, under the same conditions, to all people who are in the Spanish State. Eligibility is linked to residency, although people who do not habitually reside in Spanish territory may have their right to health care recognized in Spain by another legal title. This would be the case, for example, for those who have the right to health care under the protective action of social security, for Spanish residents abroad, and for returnees.

Since 1989, health care has been universal and funded through different taxes and payments, via contributions deducted from the monthly salary of residents. Health responsibility is devolved to each of the 17 autonomous regions, which each have their own health department—responsible for all the health centers, services, and facilities in that particular region. The central government provides this service directly in the autonomous cities of Ceuta and Melilla; it also carries out general and basic coordination tasks between the different regions.

The Spanish National Health System (SNHS) is structured into primary care and specialized care. Primary care (first-level health services) is easily accessible and capable of tackling the most common ailments. It makes basic services available within a 15-min radius from any place of residence and it is the first and major face-to-face access

point to health care. The main facilities are healthcare centers, staffed by multidisciplinary teams comprising general practitioners (family doctors), pediatricians, nurses, administrative staff, and, in some cases, social workers, midwives, and physiotherapists. Specialized care (second-level health services) comprises the most complex and costly diagnostic and therapeutic resources. Citizens obtain access to these resources by referral from primary-care doctors. The patient, along with their clinical information, is subsequently referred back to the primary-care doctor, who obtains a comprehensive clinical overview and ensures the provision of continuous care.

The basic services consist of preventive, diagnostic, therapeutic, rehabilitation, and health maintenance and promotion activities. The primary-care level covers general medicine, pediatrics, disease prevention, health promotion, health education, and rehabilitation, while specialized care includes all medical and surgical specialties. There is also a 24-h care mechanism for emergency health care. In case of a medical emergency, people can go straight to a hospital if they are physically able or call 112 to get an ambulance and be treated in a public hospital. Most emergency healthcare services are received at hospitals and healthcare centers, but exceptionally they can be received at home. In order to treat complex or rare pathologies, or indeed any pathology requiring a high degree of technological and professional specialization, there are referral centers, services, and units.

The SNHS provides supplementary services, as well as pharmaceutical, orthopedic and prosthetic services, nonurgent healthcare transportation, and diet therapy treatments. The pharmaceutical service is funded by the public healthcare system and covers the vast majority of medicinal products authorized in Spain, along with certain medical devices. A number of products are expressly excluded, such as homeopathic medicines, cosmetic products, dietary supplements, nonprescription medicines, or medicines from nonfunded therapeutic groups for the treatment of minor symptoms.

According to the Ministry of Health (2022b), the SNHS comprises 158 000 doctors, 198 000 nurses, and 330 000 other healthcare professionals. They provide care in 3000 centers, 10 000 doctors' offices, and 2000 outpatient accident and emergency services. The SNHS has 3000 ambulances, 464 hospitals with 114 000 beds and 19 000 outpatient hospital places, and 297 reference centers. Spain spends €81.6 billion a year on public health care and €33.8 billion a year on private health care (i.e., a total of €115.4 billion each year). Satisfaction with the public healthcare system is 6.6 on a 10-point scale (Ministry of Health, 2022b). The perception of good coordination between healthcare levels is less than 50%. Most people state that they participate in decision-making

regarding their health condition and treatment in both primary care (78%) and specialized care (74%).

Legislation and policy regarding people with ID

In Spain, the legal framework for ensuring the rights of people with disability is derived from national and international norms and declarations of principles, which have led to the progressive promulgation, adaptation, and improvement of specific laws and policies at the national and local levels (Citarella et al., 2020). Article 49 of the Spanish Constitution states the rights of people with disability and explicitly acknowledges the role of preventive care, rehabilitation, and treatment, and delegates the role of legislating for these purposes to the public authorities. At the supranational level, Spain signed and ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD; United Nations, 2006), which states in Article 25 that “all persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (p. 20). Since 2008, this international regulatory text has been part of the Spanish legal system.

The most recent Spanish legislation specifically dedicated to people with disability is the General Law on the Rights of People with Disabilities and their Social Inclusion (Royal Legislative Decree 1/2013). This General Law aims to guarantee the right to equal opportunities and treatment, as well as the full and effective exercise of rights by people with disabilities on equal terms with respect to other citizens. This Law prescribes a variety of services for guaranteeing health assistance to people with disability and, for this purpose, public administrations must establish programs of lifelong learning for all professionals working in the healthcare system (Citarella et al., 2020).

THE ORGANIZATION OF HEALTH CARE FOR PEOPLE WITH ID

Although there are general rules for the State, not to mention funds to provide social services, the regulation of care services in Spain is highly complex. This is because the autonomous regions have legal responsibility and can therefore set their own rules about coverage, how to provide services, and how to finance them. The public system of social services is financed mainly from the budgets of the autonomous regions, from contributions of the general budgets of the State and, in some



cases, also by users' contributions (i.e., copayment). The main model of care is public–private collaboration (García-Sabater, 2020). Access to these services for people with disability is a priority for public authorities operating in health, education, and social services, but also for third sector organizations (e.g., *Plena inclusión* (2023), *Down España*). The latter are coordinated by the Committee of Representatives of Persons with Disabilities (CERMI), an umbrella organization representing the interests of people with disabilities in Spain and guaranteeing their equal opportunities, human rights, and full inclusion in society.

In Spain, no specific policy to promote life in the community for people with ID has been developed. The support needs of people with disabilities are usually addressed in residential institutions and day centers. There are currently approximately 50 000 people with ID living in residences and many more are on lengthy waiting lists. Those with more extensive support needs especially face many situations of social exclusion and violation of rights: 16 591 people with ID and extensive support needs continue to live in institutions: the support they receive is mainly focused on residential care (32%) and day-care centers (28%), with other resources to promote inclusion in community living being vestigial (Esteban et al., 2021). Although the number of people in large residential institutions is decreasing (Martínez-Leal et al., 2011), data reflect the institution-based model that prevails in Spain for people with more significant disabilities, to the detriment of other services that are more inclusive and consistent with the content of Article 19 of the CRPD, such as personal assistance and independent living.

The Law for the Promotion of Personal Autonomy and Care for Dependent People (Law 39/2006 of December 14) regulates social protection resources through economic benefits and services (i.e., prevention of situations of dependency and promotion of personal autonomy, telecare, home help, day and night centers, and residential care). These resources are allocated depending on whether they support older people or people with different types of disability (e.g., day center for people with ID, day center for people with physical disability). Also, independent living support systems are part of a catalog of services and benefits intended to support daily living for people with a legally recognized dependency (e.g., personal assistant services, sheltered housing).

Although there should be no differences in the health care received by people with and without disability (and also between people with different types of disability, including those with ID), several studies show that people with disability do not receive the required level of

provision. Meseguer et al. (2010) observed major differences by gender and by disability status: 18% of women and 8% of men with a moderate or severe disability declared that on at least one occasion they had not received medical assistance when it was needed, as compared with 4% of women and 2% of men without disability. The most common cause, in around a third of the cases, was that there was a long wait, they were unable to secure an appointment, they were impeded by family obligations or work, they were too nervous, or they had no transport. With the goal of adapting to the demands and characteristics of this population, some autonomous regions are issuing a card that grants priority care to people with ID and allows them to bring a companion to most medical appointments (*Plena inclusión*, 2023).

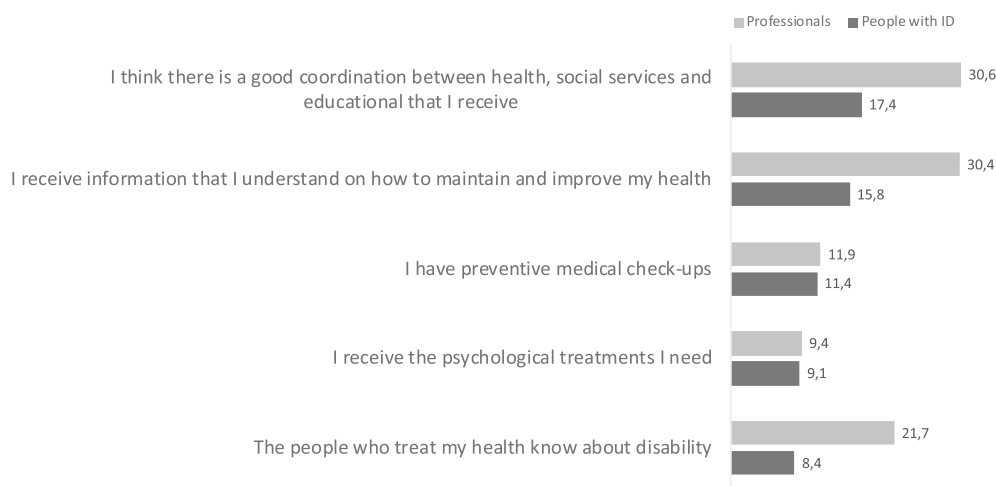
Despite Spain having generally satisfactory and adequate health and social care systems, the threat posed by COVID-19 revealed that they are not egalitarian. The severity of the disease and the consequences of the lockdown did not affect everyone equally. As observed by Navas et al. (2021), although people with ID generally received the assistance they needed, those living in specific settings (facilities for people with ID depending on organizations) had fewer natural supports, while those living with their family relied heavily on relatives. In addition, Amor et al. (2021) found that a significant proportion of people with ID (20%) who were living in disability-related services had to change their living context because of the pandemic and lockdown, which had a deleterious effect on their emotional well-being and occupations.

Studies have also shown that people with ID tend to have lower levels of access to mental health services (Gómez et al., 2021; Salvador-Carulla et al., 2013; Salvador-Carulla & Symonds, 2016). The individual autonomous regions are responsible for incorporating the necessary specifications for the specialized care of people with ID in their mental health plans. This leads to a large degree of heterogeneity across regions, with some making considerable progress in mental health-care systems, but most of them are focused on the principles of deinstitutionalization rather than on alternative community-based mental health services (Salvador-Carulla et al., 2010). For example, in Madrid, Girona, and Barcelona there is a specialized mental health service for adults with ID, accessible by referral from primary care or social services. Elsewhere in Spain, however, there is a general lack (especially in rural areas) of specialized and accessible mental health services for people with ID, insufficient monitoring and evidence about the deinstitutionalization process, and an urgent need to improve coordination within and across social and health care and to reduce geographical disparities

TABLE 1 Recent publications about health care and people with ID in Spain.

Authors (year)	Type of study and topic
Alonso-Sardón et al. (2019)	Cross-sectional study involving 162 institutionalized people with ID. The measurement tool was a structured questionnaire completed during an individual/family interview. The study showed that mental health was rated worse than physical health. People with ID and a higher degree of personal autonomy determined by institutional and family support reported better health and quality of life.
García et al. (2020)	Cross-sectional study involving 362 informants about 1040 people with ID (ad hoc survey) and 12 172 people without ID (secondary data analysis). Chronic constipation, urinary incontinence, thyroid disorders, and obesity were the most prevalent chronic diseases among people with ID, who were affected by these health conditions more frequently than people without ID.
Muñoz and de Araoz (2021)	Given the saturation of healthcare facilities and the scarcity of resources during the COVID-19 pandemic, many decisions were made without taking into consideration the rights of people with ID. This is a theoretical article in which the authors reflect on the situation created during the pandemic and relevant conclusions are drawn for the preservation of the right to health.
Navas et al. (2019)	Cross-sectional study involving 369 professionals (58%) and family members (42%) who replied to two open-ended questions about the improvements they believed should be introduced to ensure optimal access to health care for older people with ID. They emphasized the need to improve disability training for healthcare practitioners and highlighted the urgent need for flexibility in the structure of a healthcare system that has overlooked the specific needs of people with ID.
Vilaseca et al. (2017)	Cross-sectional study involving 2160 families with a family member with ID in Catalonia. Their answers to an ad hoc questionnaire showed that specialized healthcare services were the first need for people with ID.

Abbreviation: ID, intellectual disability.

**FIGURE 1** #Rights4MeToo Scale items with the highest percentages of disagreement with the statements.

(Gómez & Navas, 2021; Gómez et al., 2021; Salvador-Carulla et al., 2010).

RECENT STUDIES

Table 1 summarizes recent publications about healthcare provision in Spain for people with ID, highlighting some of the areas of discrimination faced by this group.

Currently, a research project titled #Rights4MeToo (Gómez et al., *in press*) is being conducted in Spain. In

this ongoing project involving 555 people with ID (46% women), aged between 18 and 67 years old ($M = 39.4$; $SD = 12.6$), 20% of participants showed challenging behaviors and 4% exhibited conduct disorders. More than half (59%) were taking medication, including 20% who were taking antiepileptics and 19% who were taking antipsychotics. These results accord with those from another recent study conducted in Spain: In a sample of 991 people with ID over 45 years old, García et al. (2022) found that behavioral problems were the most frequent mental health condition (54% in their sample) and antipsychotics



were the most widely used psychotropic medication (28% in their sample).

The aim of the #Rights4MeToo project is to use the quality of life framework to monitor the implementation of the Articles ratified in the CRPD (Gómez, Morán, Navas, et al., 2022; Gómez et al., 2021). Within the framework of this project, the #Rights4MeToo Scale (Gómez, Morán, Al-Halabí, et al., 2022; Gómez et al., *in press*) has been developed and is currently being validated with a broad Spanish sample. The field-test version of this scale comprises 153 items distributed across eight quality of life domains and CRPD articles. All items are answered using a 4-option Likert-type response format (from *totally disagree* to *totally agree*). Instructions, items, and answer format were validated with easy reading standards by people with ID (UNE 153101:2018 EX).

One of the CRPD articles explored in the #Rights4MeToo Scale is the right to habilitation/rehabilitation (Article 26), which is evaluated through 14 items. On the one hand, these 14 items were completed by 438 people with ID (47% women; 18–67 years old), who gave their opinion about the health care they receive. On the other hand, professionals supporting people with ID answered the same questions with their opinion about the care provided by healthcare staff to another 484 people with ID (47% women; 18–67 years old). Both groups of respondents highlighted the same five key areas in which the system was lacking: coordination across services; user-friendly information to maintain or improve their health; psychological treatments; preventive medical check-ups; and knowledge about disability among health professionals (Figure 1).

DISCUSSION

Although the right to health is recognized and protected by national legislation, people with ID seems discriminated against by the Spanish health system. Despite presenting more health problems than the general population, they consult health services less frequently due to innumerable barriers, such as lack of accessibility, underdiagnosis, and overtreatment (Leturia et al., 2014). The barriers that people with ID face and the reasons behind this discrepancy between health needs and care must be investigated as a matter of urgency. In Spain, to adequately care for people with ID, public and private health services must be physically and cognitively accessible, guaranteeing access to information and data confidentiality. Provision should incorporate a flexible, integrated and comprehensive care approach (socio-health care) throughout the life cycle. Furthermore, these services should be provided by health personnel who are

adequately trained in disability. There is a need to increase the length of medical appointments, reduce waiting times, create protocols and prevention campaigns targeting people with ID, and provide preferential access to services (Navas et al., 2019). Furthermore, to ensure the right to health for people with ID, natural supports need to be developed for those living in accommodations owned by disability organizations, while the provision of professional supports should also reach people residing in their homes (Navas et al., 2021).

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

ETHICS STATEMENT

This research was authorized and supported by the Ministry of Social Rights and Welfare of the Principality of Asturias, as well as the Research Ethics Committee of the University of Oviedo (17_RRI_2021). All participants provided their informed consent. Confidentiality and anonymity of the responses were guaranteed by not collecting personal data that could identify the participants.

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Healthcare for people with intellectual disabilities in the Netherlands

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Abstract

In this article, we describe the healthcare system for people with intellectual disabilities (ID) in the Netherlands. The general background about healthcare for people with ID is the same worldwide: their health needs are often unrecognized and unmet. We delineate, from a historical perspective, the steps the Netherlands has taken to change the situation for them. The Netherlands crossed a milestone in 2016 when it ratified the UN Convention on the Rights of Persons with Disabilities. Despite challenges in establishing numbers, an estimated ID prevalence of 1.45% was determined. The Dutch healthcare system has different levels, is funded through six distinct laws, and is complicated. The Netherlands has a spectrum of disability care services that increasingly collaborate in shaping the care of people with ID. People with ID and their representatives are increasingly involved in the process of shaping this care. The general practitioner plays a central role in the Dutch healthcare system, serving as the gatekeeper to medical specialists. Furthermore, the Netherlands recognizes the role of a physician for people with ID as a medical specialization. The core competencies of the ID physician include knowledge of the etiology and consequences of ID and associated health problems. The ID physician also knows how to deal with diagnostic and therapeutic barriers. Key challenges facing ID healthcare in the Netherlands include difficulties supporting people with ID due to the increasing complexity of society, concerns about continuity of care at the transition age (18–/18+), inadequate reach of population screening programs for people with ID, and limited availability of (routine) data for research on the ID population. The Dutch government encourages research in the ID field to overcome these challenges by financially supporting academic collaboratives. Substantial progress has been made, but key challenges remain, showing that there is still great room for improvement.

KEYWORDS

healthcare practice, ID medicine, ID physician, intellectual disability, interprofessional collaboration

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GENERAL BACKGROUND

There are a number of incentives to improve health and healthcare for people with intellectual disabilities (ID). The prevalence of health problems is higher in people with ID than in the general population, yet their health needs are often unrecognized and unmet (Cooper et al., 2004; van Schrojenstein Lantman-de Valk & Walsh, 2008). Health inequity is also demonstrated in the high rates of premature death among people with ID (Trollor et al., 2017). Improving health not only improves longevity but, above all, boosts well-being and quality of life (Tracy & McDonald, 2015).

The UN Convention on the Rights of Persons with Disabilities (CRPD), which was ratified by the Dutch Government in 2016, declares that persons with disabilities have the right to enjoy the highest attainable standard of health (Dutch Government, 2022a; United Nations, 2006). Furthermore, the CRPD states that access to health services should be provided to the same extent, quality, and standard as free or affordable healthcare services is offered to the general population. Persons with disabilities require special health services because of these disabilities. These health services should be designed to minimize and prevent further disability in all age groups. Early detection and intervention must be part of these services.

In this paper, we present an overview of Dutch demographics, organizational and financial healthcare structure, national policies, and practices aimed at improving health and healthcare for the ID population. We also describe the challenges and unique characteristics of the Dutch healthcare system in relation to people with ID.

DUTCH GENERAL HEALTHCARE SYSTEM

Demographics

The total Dutch population stands at 17.8 million people (CBS, September 24, 2023). The Netherlands has no central registration system for people with ID. In the Netherlands, the estimated number of people with ID ranges between 142 000 and 440 000, depending on definitions and methodologies. It is estimated that there are 68 000 people with an IQ < 50 and 10 000 people with severe and multiple disabilities in the country (Dutch Government, 2022b; VGN, 2022). A recent Dutch study linking several databases from public services indicating an ID diagnosis gave an ID prevalence estimate of 1.45%. The prevalence of ID was lower among females (1.2%) than it was among males (1.7%) (Cuypers et al., 2021).

Organization and financial structure of the Dutch healthcare system

The Dutch healthcare system is based on the following universal principles: accessibility and availability to all, with solidarity through mandatory medical insurance (Zorginstituut Nederland, 2022). The system can be divided into three interconnected segments: public healthcare, curative healthcare, and long-term healthcare (Figure 1).

Public healthcare encompasses population screenings, vaccination programs, and youth care. Curative healthcare comprises both physical and mental healthcare. The curative system can be divided into three levels: primary, secondary, and tertiary care. In the tertiary care level, the most specialized care is delivered, while the most general care is provided at the primary care level. Long-term healthcare includes nursing homes for vulnerable elderly people and residential care facilities for people with ID. We are going to introduce the ID physician who works in both long-term care (LTC) facilities and ID outpatient clinics. Later, we will describe the work of this doctor in detail. The arrows (see Figure 1) reveal that the systems are interconnected and there is a need to collaborate to provide optimal healthcare, especially for complex patient groups such as people with ID, as two recent papers show. One paper indicates that stakeholders caring for people with ID work together to improve access to and the quality of primary care services for all people with ID (Ieder(in), 2020). The other paper reveals that out-of-hours care for people with ID living in LTC facilities could be provided by a wide variety of health professionals, including GPs from the curative healthcare system (Heutmekers et al., 2016). Although cooperation is necessary to guarantee optimal care, it is often hampered by the complicated healthcare-related acts that regulate financial compensation.

The Dutch healthcare system is administered by six healthcare-related acts (WPG, ZVW, GZSP, WLZ, WMO, and Jeugdwet; Table 1) that form the basis for the financial structure of the health system. Each part of the healthcare system is governed and funded by its own law, as shown in Figure 1. A standard insurance package to cover the costs of basic healthcare expenses is legally obligatory for every person who lives in the Netherlands (Dutch Government, 2022c) and allows access to all parts of the healthcare system.

The total care expenditures for the general population is over 80 billion euros, of which total care expenditures of people with ID amount to 9.6 billion euros (12% of the total care) (Dutch Government, 2022d).

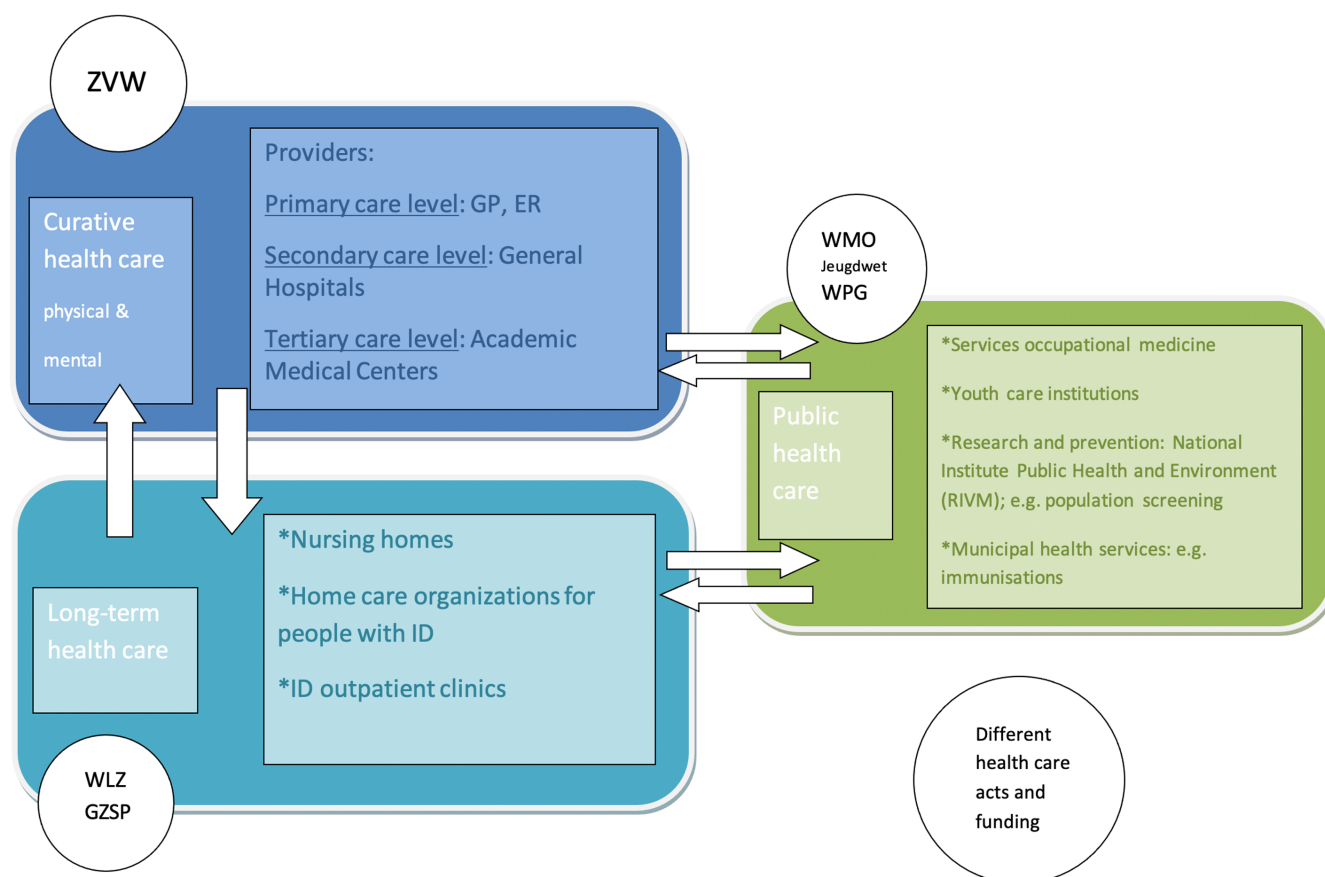


FIGURE 1 The Dutch healthcare system: three interconnected segments, governed, and funded by their own laws.

TABLE 1 Different Dutch healthcare acts.

Abbreviation	Dutch	English
WPG	Wet Publieke Gezondheid	Public Health Act
ZVW	Zorg Verzekeringswet	Health Insurance Act
GZSP	Geneeskundige Zorg Specifieke Patiënten groepen	Medical Care Act for Specific Patient groups
WLZ	Wet Langdurige Zorg	Long-term Care Act
WMO	Wet Maatschappelijke Ondersteuning	Social Support Act
Jeugdwet	Jeugdwet	Youth Protection Law
WZD	Wet Zorg en Dwang	Care and Compulsion Act
AWBZ	Algemene Wet Bijzondere Ziektekosten	Exceptional Medical Expenses Act

ID-specific legislation and policy

In 2020, a new law that is tailored to the specific populations of people with ID and people with psychogeriatric conditions (such as dementia) was introduced. WZD (Care and Compulsion Act; Table 1) regulates the rights of people with ID who receive involuntary care (Dutch Government, 2023). This law also controls involuntary enrolment into care and ensures that restriction of freedom and involuntary care is prohibited unless there is no other option. WZD applies not only in LTC facilities but

also, for example, to homes, guest accommodations, and small-scale living arrangements.

ORGANIZATION OF HEALTHCARE FOR PEOPLE WITH ID

Organization of disability support services

The spectrum of disability services includes (special education) schools, (supported) employment, daycare

facilities, ambulatory care and family support, respite facilities (after-school care, weekend care, and sleepover facilities), crisis care (intervention and shelter), ID outpatient clinics, and residential care.

Daily care and support are delivered in accordance with an individual care or support plan and are primarily coordinated by parents or relatives (when people with ID live with their families) or by a professional caregiver (when people with ID live in a residential care facility). Behavioral specialists and ID physicians together with support workers, GPs, and specialized therapists, such as physical therapists, occupational therapists, and speech and language therapists provide holistic and interprofessional care.

In the last few decades, ID physicians, support workers, behavioral specialists, and specialized therapists in ID care have created professional profiles and codes dedicated to ID care, founded (ID-dedicated sections of) professional associations, established their own specialized training and seminars, and developed professional guidelines. These specialized associations are involved in the development of interdisciplinary guidelines and are funded by the Ministry of Health, Welfare and Sport, specifically for LTC, in close collaboration with interest groups for people with ID.

If the daily care of a person with ID poses major problems, the National Centre for Consultation and Expertise (CCE) team can be consulted. CCE offers supplementary expertise and support to professional networks of individuals with ID in need of intensive LTC because of severely compromised quality of life due to highly challenging behavior (CCE, 2022).

Organization of disability healthcare services

Historical and societal context

Although the first residential care facility for people with ID was established in the Netherlands in 1891, it was not until 1945 that the first professionals, medical doctors, and nurses emerged to take the lead in the professional care of people with ID. Due to the introduction of AWBZ (Exceptional Medical Expenses Act; Table 1) in 1968 that provided general insurance covering special healthcare needs, institutional care expanded rapidly and residential places increased from 10 000 to 36 000 in 2004. These residential facilities were not all institution-based; rather, some were also community-based (communal living has been provided since the 1960s). During the 1960s and 1970s, behavioral specialists entered the field of ID care. The process of deinstitutionalisation in the Netherlands

began much later and was slower than in other countries during the 1980s and 1990s. Gradually, nurses in ID care were replaced by social care or support workers, and nursing expertise was substituted with social care expertise ('s Heerenloo, 2007; Buntinx & van Gennep, 2007).

Since the 1990s, there has been growing interest in people with ID from the fields of both medical and social science. In 2002, the Council for Public Health and Care (Dutch: RVZ) published the report 'Community Care and Community Living', indicating that healthcare for people with ID did not meet the standards of modern healthcare for the general population in the Netherlands (Raad voor de Volksgezondheid en zorg, 2002). Both access to mainstream health services and the availability of specialist health services were inadequate, and action was needed. RVZ looked into specific ID-related care gaps and proposed the directions and conditions for optimal healthcare for people with ID in the Netherlands (Evenhuis, 2002).

The European Manifesto for Basic Standards of Healthcare, first presented in 2003, prescribes standards for high-quality and accessible healthcare for individuals with ID and offers guidance on how to resolve care gaps; improve the ID expertise of health professionals, educators, and researchers; enhance the multidisciplinary approach to ID healthcare; increase specialist healthcare services; and promote proactive and personal health management for people with ID (Meijer et al., 2004). Currently, medical doctors and behavioral specialists generally cooperate and pool their expertise. Today, individuals with ID and their parents or relatives are increasingly regarded in care, policy, and science as experts to collaborate with.

Primary care vs. specialized ID care

The GP is the key figure in Dutch primary healthcare. The basic principle in the Netherlands is that all citizens should be registered with a GP. This principle also applies to people with ID who live in the community and increasingly to people with ID who live in residential care facilities. However, there is a looming shortage of GPs.

In 2000, the Dutch Minister of Health initiated ID medicine because of the unmet health needs of people with ID and the lack of a dedicated medical specialty to address these special health needs. This initiative resulted in a specialist three-year postgraduate training program and the recognition of the role of ID physicians as a medical specialization. Subsequently, there was a necessity for the scientific study of these special health needs to improve healthcare for the ID population in the Netherlands.

TABLE 2 Research papers produced by ACs.

Academic collaborative for ID	Focus	Publication topic	Publication type	Reference
Healthy Aging in Intellectual Disabilities	The improvement of the physical and mental health of people with ID and particularly determining the prevalence of and engaging in the detection and management of common (age-related) health problems and associated factors	Healthy aging and ID	Research report	De Leeuw et al. (2022)
		Antipsychotic withdrawal in adults with ID and challenging behavior	Research report	Beumer et al. (2021)
Intellectual Disability and Mental Health	The perspective of people with ID and their families as experts, and interprofessional collaboration to improve understanding and management of mental and behavioral disorders, which may or may not be associated with physical health problems	Prevalence of antipsychotic drug use	Research report	de Kuijper et al. (2010)
Stronger on your own feet	Outlining the mechanisms behind complex health problems that people with ID encounter in their lives and the health systems and the policy in relation to people with ID in order to unravel and prevent health inequities and disparities that people with ID experience	Cancer treatment and decision-making in individuals with ID	Review	Boonman et al. (2022)
		All-cause and cause-specific mortality among people with ID during the COVID-19 pandemic	Research report	Cuyppers et al. (2023)

Approximately 235 ID physicians work in the Netherlands. ID physicians are generally employed by care providers for people with ID although, recently, an increasing number of ID physicians have started working independently. Initially, ID physicians delivered medical care to people with ID in residential care facilities. However, progressively, ID physicians became available, upon referral, through outpatient clinics for children and adults with ID who live with their families or who live, with ambulatory help, independently (Moonen et al., 2022).

There are currently approximately 80 ID outpatient clinics spread across the Netherlands, supporting GPs, medical specialists and psychiatrists in the physical and mental healthcare of people with ID. These outpatient clinics are often embedded in an interprofessional setting: behavioral specialists and ID physicians join specialized therapists in outpatient clinics affiliated with an ID care provider and a variety of medical specialists in academic hospitals. ID physicians are also affiliated with centers of expertise for genetic syndromes located in academic hospitals, which are connected with international reference networks.

The core competencies of the ID physician include (a) management of etiology-related health problems, (b) addressing multiple and complex health problems that often present with atypical complaints, (c) anticipating and dealing with ID-related diagnostic and therapeutic

challenges, (d) addressing consent capacity issues, (e) adopting a functional approach, and (f) promoting participation and enhancing quality of life.

RESEARCH AND PUBLICATIONS

Since 2019, the Dutch Ministry of Health, Welfare and Sport has promoted centers of expertise in LTC and academic collaboratives (ACs). Centers of expertise in LTC aim to improve the quality of life and care of people with rare conditions and complex support needs (Government, 2022a). National networks dedicated to people with these rare conditions are currently being built and are composed of an academic knowledge center, one to four national centers of expertise, and several affiliated regional centers of expertise (Koopmans et al., 2022).

ACs for ID aim to create a robust research infrastructure in LTC and encompass close collaborations between university medical centers and regional LTC organizations. The aforementioned national networks perform research based on questions relevant to practice and to people with ID and their families, disseminate relevant outcomes (via education and accessible communication), and then translate results into practice. The networks closely collaborate in cross-domain research on



complementary research themes: behavior, social inclusion, and/or participation in society and health. Three out of eight of the current academic research centers focus on ID medicine.

Collaboratives prioritize the expert perspectives of people with ID and their families and interprofessional collaboration to clearly understand and manage physical and mental health problems. The collaboratives also investigate the delivery of healthcare and policy. Simultaneously, the work of collaboratives enhances approaches to service user empowerment in health and medical care for people with ID (Table 2). All ACs pay attention to conducting inclusive research (Frankena et al., 2019).

DISCUSSION

Healthcare for people with ID requires an understanding of their health needs and making efforts to meet these needs. Presently, specialized ID care is increasingly shaped through a multidisciplinary partnership in which persons with ID and their legal representative, if applicable, participate. ID physicians who are trained in this field of expertise play an important role in the provision of medical care for this population in the Netherlands. ID outpatient clinics aim to assure proper access to specialized care and attendance provided by ID physicians for all people with ID. Outpatient clinics can provide support to GPs, medical specialists and psychiatrists to promote equal access to mainstream health services for people with ID.

Key challenges

Although important steps have been taken in the field of specialized ID care, multidisciplinary collaboration has been undertaken between persons with ID and their legal representatives, and ID-specific research has been conducted, several challenges remain:

(1) an increasingly complicated society, with many diagnostic and treatment options in healthcare, poses a challenge for people with ID to obtain guidance suitable to their needs. (2) There is often a lack of evidence-based guidelines for providing the best treatment to a person with ID because of limited ID-specific guidelines. (3) When children with ID experience serious medical problems that cannot be solved by a GP, they can go to a pediatrician just like any other child. However, from the age of 18 and above, healthcare provided by the pediatrician is no longer reimbursed. Although there are ID physicians in the Netherlands who could take over the task of a pediatrician at the age of 18, their workforce is too

small. In addition, the various healthcare acts described earlier make it difficult to obtain reimbursement for the healthcare provided by the ID physician. Moreover, the ID physician works in primary care and does not have access to the same hospital facilities as the pediatrician. (4) There is an absence of a central registration system where people with ID can be identified in the Netherlands. This absence hinders their visibility in the population and prevents access to routine data for research. To collect anonymized data for research, systems must be linked together, which is a complicated and time-consuming process (Cuypers et al., 2021). (5) National screening programs such as those for breast and colon cancers are available to all Dutch people. Research reveals that these programs do not always reach people with ID (Chan et al., 2022). (6) Presently, in over 50% of people with moderate-to-profound ID, a genetic diagnosis can be established (Vissers et al., 2016). Identifying genetic conditions associated with physical and mental health problems helps improve the understanding and management of health problems (Adlington et al., 2019). All people with ID should be granted genetic examinations in order to optimize their care. (7) Although great attention is paid to the implementation of research into practice as a major focus of ACs, this implementation remains a challenge. It is not easy to change existing routines and working methods. Implementation science is practiced in all levels of healthcare and deserves attention within ID healthcare too. (8) The shortage of healthcare professionals is increasing at all levels (primary, secondary, and tertiary). This shortage, along with financial sustainability, is a cause for concern.

CONCLUSION

Healthcare for people with ID in the Netherlands is constantly evolving. Significant steps have been taken in many areas in recent years, but key challenges remain, showing that there is still great room for improvement.

AUTHOR CONTRIBUTIONS

Sylvia Huisman: literature search/review, drafted and revised the manuscript, and approved the final version of the manuscript. Dederieke Festen: literature search/review, drafted and revised the manuscript, and approved the final version of the manuscript. Esther Bakker-van Gijssel: literature search/review, drafted and revised the manuscript, and approved the final version of the manuscript.

CONFLICT OF INTEREST STATEMENT

No funding source, no conflicts of interest.

ETHICAL STATEMENT

I confirm that all research/article meet the ethical guidelines and legal requirements.

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Health care for persons with intellectual and developmental disabilities in India

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Abstract

Legislations for persons with disabilities emerged in the 1990s in India, providing them with rights and entitlements. Aligned with the UNCRPD, the Rights of Persons with Disabilities Act (2016) supports improved programmes and services. There are no exclusive policies for those with intellectual and developmental disabilities. Different government departments and non-government organisations provide services including centrally sponsored programmes to persons with disabilities and enable them to exercise their rights. For example, rehabilitation and provision of aids and appliances lie with the Ministry of Social Justice and Empowerment, right to education is with the Ministry of Education, and, early intervention and health services and related supports are with the Ministry of Health. In India, non-government organisations also play a vital role in health care services. In this paper, we discuss the existing health care systems including medical services in India for persons with disabilities with a specific focus on persons with intellectual and developmental disabilities. The discussion includes how the system was evolved and what is in place today, the coverage, strengths, and limitations in the system. We have tried to provide a comprehensive description of existing policies, and practices of health care as well as the cultural influences with regard to health care for people with intellectual and developmental disabilities in India.

KEYWORDS

developmental disabilities, health care in India, health insurance, intellectual disability, medical facilities, policies and practices in health care

Abbreviations: ASHA, Accredited Social Health Activist; AYUSH, Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homeopathy; BCE, Before Common Era; CE, Common Era; DEPWD, Department of Empowerment of Persons with Disabilities; DGHS, Director General of Health Services; GDP, Gross Domestic Product; ICDS, Integrated Child Development Services; IDD, Intellectual and Developmental Disabilities; MoHFW, Ministry of Health and Family Welfare; NGO, Non-government Organization; NHP, National Health Policy; NIEPID, National Institute for the Empowerment of Persons with Intellectual Disabilities; PHC, Primary Healthcare Centre; PwD, Person with Disability; RBSK, Rashtriya Bal Swasthya Karyakram; SOB, Special Olympics Bharat; UDID, Unique Identification Document for Person with Disability; UNCRPD, United Nations Convention on Rights of Persons with Disabilities.

INTRODUCTION

India is an amalgam of cultures, traditions, religions, languages, philosophies, beliefs, and customs with varied geographical terrains and the people of India celebrate diversity in their heritage. The spirit of India has fascinated the world with its unique and mystique culture, and its history is punctuated by constant integration with migrating people (Muller, 1888). Susruta's (800–600, BCE), monumental treatise on Surgery, '*Susruta Samhita*' established him as the Father of Indian Surgery (Raju, 2003). Charaka, the Indian physician who is supposed to have lived between second century BCE and second century CE, delved into all aspects of medicine, including the logic and philosophy behind the Indian medicinal system; he placed special emphasis on the diagnosis of diseases and treated 'Ayurveda' as a comprehensive system of health care that dealt with both preventive and curative aspects (Britannica, 2014).

The Indian medical system had referenced to disabilities including intellectual and developmental disability (IDD) since ancient times. To quote an example, Ayurveda (1000 BCE) categorises intellectual disability as '*janma bala pravrt*' or congenital ailments resulting in impaired mental functioning with or without physical disabilities, and the word '*jadata*' mentioned in Ayurvedic texts refers to intellectual disability including 'mental sub normality and related disabilities (Agarwal et al., 1999). While keeping pace with the technological developments and not losing track of the ancient indigenous medical systems; India has come a long way since early centuries in terms of medical and health care in general, and provision for persons with disabilities (PwDs) in particular.

PERSONS WITH IDD AND CULTURAL INFLUENCE

Census of India (2011) reported the population of the country to be 1.2 billion and has the highest estimated population in the world of 1.43 billion surpassing China (UN, 2023). With regard to population having disabilities, Census of India, 2011 reports that 26.8 million (2.2%) people have disabilities of which 1.5 million have intellectual disability (MoSPI, 2021).

Hinduism, a major religion in India believes in 'Karma' and rebirth which leads to belief that the effects of good or bad deeds of an earlier birth have a consequence in the present birth. Having a child with a disability is believed by many, to be the effect of earlier bad deeds (Waldman et al., 2010). No matter where they live, most Hindus tend to have this belief. Gabel (2004)

conducted a study in the United States on the cultural practices among South Asian immigrants and found the belief in them that having a child with intellectual disability is due to bad Karma which can be resolved by doing good deeds in the present birth. Many families, tend to carry out rituals in temples to ward off the bad deeds thus expecting improvement in the child with disabilities. It also happens that the parents as they do 'doctor shopping' looking for a cure, get cheated by black magicians, and quacks. There are also parents, irrespective of the religion, who believe that they are the 'chosen' parents by the Almighty to look after a challenging child. Many a time, counselling parents on answering 'Why me?' is less frequently encountered as they would already be at 'what next?' stage, due to their belief in karma or the will of God.

GENERAL HEALTH CARE SYSTEM IN INDIA

The healthcare system in India for general population is one of the largest ones in the world; all citizens can get free outpatient and inpatient care at government facilities (Gupta & Patel, 2020). It is predominantly used by the poorer population in the country. Primary Health Centres (PHCs) with the basic medical facilities are established under National Health Mission (NHM), each of them designed to reach out to a general population of 30 000 in the rural areas and 20 000 in the hilly tribal and desert areas. There are about 30 045 PHCs in India of which 24 855 are located in rural areas and 5190 are in urban areas. (PIB, 2020). Furthermore, community health workers and Accredited Social Health Activists are engaged to work in the community to promote health education and preventive measures as well as referral for treatment (Girimaji, 2011). District and state capitals have well-equipped government hospitals with different specialties to cater to varied health needs. At regular intervals, specialists on disabilities (physical medicine and rehabilitation), physiotherapists and occupational therapists assess and refer patients to specialised government or private hospitals (Selvaraj et al., 2022).

THE NATIONAL HEALTH POLICIES (NHPS)

The NHP 1983 and 2002 have served well (MoHFW, 2017) and health sector improved immensely (Yadav, 2018) and the current NHP 2017 is initiated with the objective to improve health status through concerted policy action in all sectors and expanding preventive, promotive,

curative, palliative and rehabilitative services provided through the public health sector with focus on quality (MoHFW, 2017). As a result, many schemes are implemented to reach the unreached with equitable and affordable health care to the public (PIB, 2019).

The NHP 2017 aims to increase health expenditure by Government as a percentage of GDP from the existing 1.15%–2.5% by 2025 and also increase State sector health spending to >8% of their budget (MoHFW, 2017). The union budget 2022–23 has increased the budget provision on health care by 16.5% in comparison to the previous year (KPMG, 2022).

As part of NHP 2017, Ayushman Bharat, (meaning healthy India), National Health Protection Scheme a health insurance was launched in 2018 to achieve the vision of Universal Health Coverage. This initiative has been designed to meet sustainable development goals and its underlining commitment, which is to 'leave no one behind' (NHA, n.d.) insulating lower income household from high healthcare costs by offering free care to beneficiaries in private as well as public facilities (Gupta & Patel, 2020) under Prime Minister Jan Arogya Yojana which gives access to these services with a ceiling in the expenses to the poor in the government empanelled private hospitals (NHA, n.d.) with cutting edge technology and expert doctors qualified in super specialisation areas.

PROMOTING HEALTH CARE OF WOMEN, CHILDREN, AND PERSONS WITH DISABILITIES

The country has an inter-ministerial agenda to address the health issues, prevention, and referral. In addition to the schemes and policies of Ministry of Health and Family Welfare, other ministries also contribute to the medical and health-related issues particularly for women, children, and PwDs. Ministry of Women and Child Development has been implementing the world's largest and most unique outreach programme of Integrated Child Development Services (ICDS) (MoWCD, n.d.) providing a package of services comprising supplementary nutrition, immunisation, health check-up, and referral services (Sachdev & Dasgupta, 2001).

Considering the fact that indigenous medicine has been practiced in the country since early centuries, an exclusive Ministry is set up by the government called Ministry of AYUSH (MoA, 2021). While Ayush in Sanskrit language is used to refer to long life with good health, the acronym 'AYUSH stands for the indigenous medical disciplines Ayurveda, Yoga & Naturopathy, Unani, Siddha, and Homoeopathy. Traditional Systems

of medicine always played an important role in meeting the global healthcare needs (Ravishankar & Shukla, 2007) and the government recognises these disciplines and offers these services in the government hospitals too.

The National Institutes for various disabilities and the composite regional centres established by the Ministry of Social Justice and Empowerment throughout the country have specific rehabilitation measures as well as early intervention centres, providing services free of cost. Established in 1984, the National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID) develops service models, generates human resources, promotes research and development in the area of IDD. The NIEPID and its regional centres spread out in different parts of India provide free early intervention services and medical treatment to conditions such as epilepsy, and hyperactivity often seen in persons with intellectual disabilities (NIMH, n.d.).

India is one of the few first countries which ratified UNCRPD. Consequent upon signing the Convention on 30 March, 2007, the country ratified it on the 1 October, 2007. The Convention came into force from the 3 May, 2008 (DEPWD, n.d.-c). The country also aligned its legislation 'Rights of Persons with Disability Act, (RPwD, 2016)' (DEPWD, n.d.-d) with UNCRPD by replacing the earlier PwDs Act (1995). Chapter 5 (25 and 26) of the RPwD Act is exclusively on health care and insurance for person with disabilities and mandates by the respective governments and state and central level to take measures towards prevention of disabilities through care during pregnancy, early detection and intervention, reproductive health care of women with disabilities, care during natural disasters and other situations of risk, to name a few (Kothari & Raturi, 2014).

HEALTH CHALLENGES AMONG PERSONS WITH IDD IN INDIA

It is obvious that people with IDD have more health-related problems than people with other disabilities and without disabilities. In a study conducted in southern India, according to Gudlavalleti et al. (2014), people with disability (18.4%) needed to visit a hospital significantly more often compared to people without a disability (8.8%). Evidence shows a significantly higher rate (17.8%) of hospitalisation among PwDs compared to their non-disabled counterparts (5%) (Gudlavalleti, 2018). Further, the study revealed a significant difference with respect to past hospitalisation where people with disabilities had 4.6 times higher risk of suffering from diabetes and 5.8 times higher risk of suffering from depression compared to people without a disability; further the risk was

significantly higher in males compared to females with disability. Unlike conditions of other disabilities, people with IDD have cognitive challenges. This interferes with their understanding, recognising, and reporting health problems which delays or minimises chances for timely treatment (Kothari & Raturi, 2014). The health problems among elderly persons with IDD are also challenging (Shrestha & Weber, 2002) and the developing nations lack a proper system of care for such ageing persons (Menon et al., 2017).

An unpublished report of Special Olympics Bharat (SOB), through a large-scale health screening in India, it has been found that persons with intellectual disability are at increased risk of secondary health issues: 35% have untreated tooth decay; 15% have an eye disease; 35% have low bone density; 21% fail hearing tests; and 60% have at least one kind of skin or nail condition (SOB, 2021). Also, people with ID suffer from a higher burden of behaviour problems (Kishore et al., 2004) with a possibility of having psychiatric comorbidity among the people having intellectual disability (Lakhan & Ekundayo, 2017).

ORGANISATION OF HEALTHCARE FOR PEOPLE WITH IDD

In India, as such there is no specialised healthcare service for people with IDD. All the schemes, policies and provisions address all disabilities covered by the RPwD Act. Clinical services for intellectual disability are inadequate and unevenly distributed (Girimaji, 2011). The healthcare services such as medical treatment, rehabilitation, and health promotion are not well integrated. People with IDD may opt for the community health delivery system such as PHCs and hospitals for medical treatment, whereas very few institutions such as the NIEPID deliver rehabilitation services along with medical services (NIMH, n.d.). Many of the rehabilitation clinics including child guidance clinics run by various national institutes established for various disabilities, composite rehabilitation centres, district rehabilitation centres, medical colleges, and non-government organisations provide clinical services. They include clinical evaluation, physical and psychological testing, parent counselling, treatment of comorbid physical and mental disorders, and genetic counselling (Girimaji, 2011). However, the coverage is limited to a small sizeable target population.

As a branch of indigenous medicine, Ayurveda is preferred by many in India for chronic conditions. Many parents tend to reach out to Ayurveda for treatment of

their child with intellectual disability looking for 'cure'/improvement. Agarwal et al. (1999) explain that Ayurveda categorises intellectual disability as '*Janma Bala Pravrt*' or congenital ailments resulting in the impaired mental functioning with or without physical disabilities. The treatment involves using ayurvedic medicine along with strict observance of dietary regime. In recent years, controlled studies are being carried out to establish of authenticity of this type of treatment.

NATIONAL PROGRAMMES AND INITIATIVES

Department of Empowerment of PwDs at National level has introduced 'Unique ID for Persons with Disabilities' (UDID) with a view of creating a National Database for PwDs (DEPWD, n.d.-a), and to issuing a Unique Disability Identity Card based on certification of disability and enable them to receive their benefits including health and medical benefits seamlessly at all levels including village, district and state thus reaching throughout the country (UDID, n.d.). Out of three flagship programmes of Government of India for prevention and interventions related to disability as an area of concern from health sector, '*Rashtriya Bal Swasthya Karyakram*' (RBSK) was initiated during 2013 (RSBK, n.d.), similar to National Programme for Control of Blindness (DGHS, n.d.-a) initiated during 1976, and National Programme for Prevention and Control of Deafness initiated during 2007 (DGHS, n.d.-b). RBSK aimed to screen and manage children from birth to 18 years of age for 4 Ds, that is, Defects at Birth, Deficiencies, Diseases and Developmental Delays including disabilities with target to cover around 270 million children. Under this, District Early Intervention Centres, with multitude of services are offering developmentally supportive interventions at the district level for follow-up management of referred and treated cases (MoHFW, 2014). These units also link these children with tertiary-level health services, in case surgical management is required (NHM, 2022). The Ministry of Social Justice and Empowerment provides a health insurance scheme called '*Niramaya*' through the National Trust exclusively for persons with developmental disabilities, namely autism, cerebral palsy, mental retardation (Intellectual disability), and multiple disabilities (The National Trust, n.d.). In addition, the same ministry provides free supply of aids and appliances, and assistive devices and carries out corrective surgery for deformities through a scheme called 'Assistance to Disabled Persons for Purchase/ Fitting of Aids and Appliances' (DEPWD, n.d.-b).

CASE STUDY: 1

Mr. K.R. aged 24, diagnosed as having mild intellectual disability came to the National Institute for Empowerment of Persons with Intellectual Disability (NIEPID) with his father. He was referred to the NIEPID by the government hospital requesting for the opinion of the experts with regard to the surgery as requested by the father on Mr. K.R. The father narrated that his other son aged 31 required kidney transplantation and he wished to use the kidney of Mr. K.R. and that MR. K.R was willing to donate. The government hospital where the surgery was proposed to be done, referred the issue to NIEPID, the apex institute in the country for intellectual disability to get the opinion as to whether Mr. K.R.'s willingness can be accepted and the surgery can be done. The team members of at the NIEPID asked for the willingness of Mr. K.R. to donate a kidney to his brother and he agreed. When asked where the kidney is and how he would give it, he had no idea. He was explained about kidney donation in a way he would understand with diagrams. The moment he heard he would have a surgery, he disagreed totally for the donation. The father was upset saying that his son was willing but the expert team made him refuse. He too was counselled.

The surgery was prevented and the point of willingness of a person with intellectual disability in such instances has to be with his understating only was driven across clearly. Linkages of concerned departments within the system is essential for smooth service delivery. Medico legal issues related to intellectual disabilities need a focus.

ROLE OF NONGOVERNMENT ORGANISATIONS (NGOS)

NGOs in India play a major role in care, education, and rehabilitation of persons with intellectual disabilities. Kishore and Nagar (2012), in a study on role of NGOs in identification camps of PwDs, found that in comparison to the camps organised by the government, more individuals with intellectual disability were identified in the camps conducted by the NGOs. Jain and Dhir (2021) noted that most of the services being delivered to PwDs are by NGOs and the quality and effectiveness for the delivery of services depend on the capacity of the NGOs

CASE STUDY: 2

Baby M.S. aged 8 years diagnosed as having cerebral palsy and intellectual disability was receiving services from a nongovernment agency working for children with intellectual and developmental disabilities in a rural area. She was on medication for the seizures and a surgery in her leg. The parents were poor farmers and could not afford the cost of surgery and the therapies. The 'Niramaya Insurance Scheme' implemented by the 'National Trust for Welfare of Persons with Autism, Cerebral Palsy, Intellectual Disability and Multiple Disability' under the Ministry of Social Justice and Empowerment, Government of India supported her surgery and post-surgery therapies and the medication for epilepsy. The Niramaya Scheme offers an e-card to those who register and can access health care in hospitals by using the e-card. The expenses incurred are reimbursed.

This was one way of reaching the poor with long term recurring expenses due to the disability.

involved. Medical and health services are part of the overall services of these NGOs and not exclusively health services.

There have been several other attempts also. Dental Council of India entered into an agreement with SOB to cover screening and management of oral health problems (SOB, 2016a) to cover its 1 540 874 athletes having IDD (SOB, 2022), and similar effort has been adopted by Indian Dental Association (SOB, 2016b). To amplify the need and importance of inclusion in the health segment, SOB marked the World Health Day with conducting medical screenings over 100 000 children and adults with IDD across 139 locations in India by the help of 8772 trained clinical volunteers. The purpose was to expand health screenings and sensitise the medical fraternity to make health benefits accessible to everyone alike, including persons with IDD (SOB, 2022).

BARRIERS TO HEALTHCARE SERVICES

Prevalence studies show a wide range, thus not able to accurately estimate the prevalence to provide services (Russell et al., 2022). Studies from the South Asia region reveal that not only did people with disability have a

higher load of adverse health outcomes but they also faced significantly more barriers in accessing health services (Gudlavalleti, 2018). Furthermore, discussing on referrals to medical support, James et al. (2019) observed that welfare benefits in India are not comprehensive, and it takes considerable effort to avail them. The authors add that despite efforts to make the process easy, the number of referrals from mental health professionals to hospital is less in comparison to more people getting referred by snowballing. Physical inaccessibility to healthcare facilities, communication failure between professional and patients with IDD, attitudinal issues, and lack of resources and technology are of the significant barriers that can be seen in India. In order to achieve 'better health, better lives' of person with IDD (WHO, 2010); barriers such as cognitive, structural, and financial found to be consistent with the Health Care Access Barrier Model (WHO, 2011). Cognitive barriers included caregivers being unable to identify the complex health needs of their children. Caregivers lacked appropriate knowledge of intellectual disability, with doctors failing to educate them. The following Case Studies 1 and 2 are examples of one of such challenges.

Structural and financial barriers encompassed poor availability of healthcare providers and contributed to poor access to specialists. Caregivers had no information about government financial aid and healthcare providers did not refer them to these (Varghese et al., 2015). However, there are some examples how the treatment of a person with intellectual disability is supported. The following example is one of these.

NEED FOR TRAINING OF HEALTHCARE PROVIDERS

There is an immense need for training of health care providers about the needs of people with IDD. This would facilitate in establishing system of care that could integrate acute health care with long-term services. In India efforts were made by Rehabilitation Council of India through a 'National Programme on Orientation of Medical Officers Working in Primary Health Centres'. The programme was launched throughout the country in the year 1999 and implemented in two stages. In the first stage, Master Trainers including Medical and Rehabilitation Professionals were trained and in the second, the trained Master Trainers oriented the Medical Officers on disability management. Through this programme, 642 Master Trainers and 18 519 Primary Health Centre Medical Officers were trained (RCI, 2017). However, studies have indicated about insufficient input on disability components in medical education curriculum and

practice. The new curriculum of the Medical Council of India lacks disability-related competencies. This further involves the risk of perpetuating the medicalization of diverse human experiences and many medical students may graduate with little to no exposure to the principles of disability-inclusive compassionate care (Singh et al., 2020).

DISCUSSION AND CONCLUSION

Healthcare has become one of the largest sectors of the Indian economy, in terms of both revenue and employment (Sarwal et al., 2021). India's healthcare sector comprises hospitals, medical devices and equipment, health insurance, clinical trials and telemedicine, and, medical tourism (Sarwal et al., 2021) has grown rapidly over the last 5 years (IBEF, 2019). Although Ministry of Health and Family Welfare of India has released accessibility standard for health care (MoHFW, 2022), adequate investment with proper budgetary provision has not been made to make healthcare services inclusive and accessible for PwDs (Kothari & Raturi, 2014) and more specifically for IDD having a population of 26.8 million in India. Although advancement of public health, medical technology, improved nutrition, and living conditions in India, the life expectancy has improved significantly; but it has created challenges for health care of older age with IDD of having unique needs, for example, increased risk of cardiometabolic diseases (Lakhan & Ekundayo, 2017). If the behaviour problems and psychological vulnerability of the population are not adequately addressed, the risk of increased prevalence of mental disorders may escalate with the existing high prevalence of psychiatric comorbidity among the population (Kishore et al., 2004). Data on health-related challenges and use of health services is not available readily. Hence there is an urgent need to apply public health intervention to map and prevent diseases among persons with ID (Lakhan & Ekundayo, 2017) as well as approaches to health promotion must be strengthened. Also, the research focusing on healthcare needs of such people lacks significance and such research works should be encouraged. The advancement of medical sciences in the country has seen emergence of many super specialties, and similarly, developmental medicine or IDD medicine as a specialised study may be encouraged. Also, there is need for the integration of genetic screening into the public health services in India (Dave et al., 2005). As it could be seen, the health care policies are drawn out and implemented by more than one government department. However, the strengths and the difficulties in implementation and the support reaching the beneficiary with intellectual disabilities, need to be studied in depth to understand the gaps

to be filled and these findings may help in reaching the beneficiary with health care seamlessly.

As rightly observed by Bunga et al. (2020), despite lack of adequate inclusive and accessible health services for persons with IDD in India, families stand up as an institution and take the burden to look after such ailing persons. In many families, it can have a positive impact like increased self-efficacy, and parental and family general satisfaction with life which helps the parents to provide necessary care and support and face the situation more gracefully. Focussed healthcare services to persons with intellectual disabilities by the government systems will ease the load on the families and help the persons having intellectual disability and family have better quality of life. Schemes are emerging and the government is working towards it. Despite finding positive examples of policy, legislation, and practice in support of children with intellectual disabilities, there are clear gaps and areas for improvement (Scherer et al., 2023). The cultural and indigenous health practices also greatly influence the health care of persons with IDD in India.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

ETHICS STATEMENT

The article is predominately based on review of literature and documents. Wherever case studies are stated, it is done with the permission of the concerned persons after explaining to them the purpose of narrating the case study. Further, the names of the persons are changed in the case study to maintain anonymity.

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A portrait of Brazilian healthcare for people with intellectual and developmental disabilities

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Abstract

In Brazil, the Unified Health System (SUS) is the national health system that offers free medical services to all citizens including all levels of treatment and prevention of diseases, subsidized by the government. Although SUS is universally offered, people with intellectual and developmental disabilities (I/DD) face challenges regarding healthcare. This article aims to present a description of the healthcare framework for people with I/DD in Brazil, as well as to characterize the Care Network for Person with Disabilities. This is a descriptive study that reports aspects of the structure and functioning of the health system in the country. In addition, we summarize core data from the National Health Survey that characterizes the health condition of people with I/DD in the country. Although Brazil has promoted legislation in favor of the health of people with I/DD and other disabilities, the obstacle is the implementation. Overall, there have been advances in SUS efficacy. However, challenges include long waiting times for diagnosis, habilitation/rehabilitation, inadequate transportation, and insufficient staff training on disability and I/DD, particularly. In this sense, it is necessary to monitor laws and inclusive actions so that the principles of the SUS are actually applied.

KEYWORDS

Brazil, challenges, healthcare, intellectual and developmental disabilities, practice

INTRODUCTION

The Federative Republic of Brazil, known worldwide as Brazil, has the third largest territorial extension of the American continent, occupying 8.5 million km². The country is made up of 27 state units. According to the Institute of Geography and Statistics (IBGE, 2023), the total population of Brazil exceeds 203 million people, making it one of the most populous in the world.

Despite being ranked as the ninth economy in the world (IMF, 2021) with a total Gross Domestic Product

(GDP) of 9.9 trillion reais (IBGE, 2022a), those numbers contrast with a high GINI index of inequity (0.54, range from 0 [perfect equity] to 1 [perfect inequity]) (World Bank, 2021). This is explained by a history of slavery, colonialism, dictatorship, and vulnerable democracy highly endorsed by corruption. Consequently, the country has unequal political, economic, social, educational, and health conditions among the entire population. That means that resources are not evenly distributed per states and regions. For instance, contrasting the Brazilian South and Northeast regions there is a substantial difference

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TABLE 1 Sociodemographic characteristics of the regions of Brazil.

Regions of Brazil	Number of states	Life expectancy (years)	Infant mortality (per 1000)	HDI	Literacy (%)	GDP (%)
North	7	71.5	16.6	0.73	93	6
Northeast	9	72.3	15.2	0.71	87.1	14
Central-west	3 (plus FD)	72.9	13	0.78	95.6	10
Southeast	4	73.4	11.9	0.79	97	53
South	3	74.3	10.2	0.83	97	17

Note: Data compiled by the Ministry of Health (2019–2020) and IBGE (National Household Sample Survey Continuous 2022).

Abbreviations: FD, Federal District; HDI, Human Development Index; IBGE, Institute of Geography and Statistics; GDP, Gross Domestic Product.

TABLE 2 Types of disabilities in Brazil.

Types (persons aged 2 years and older)	Total (millions)	(%)
With some disability	17.2	8.4
Physical (lower limbs)	7.8	3.8
Visual	7.0	3.4
Physical (upper limbs)	5.4	2.7
Multiple Disability	5.3	2.6
Intellectual	2.5	1.2
Hearing	2.3	1.1

Note: Data from the National Health Survey (IBGE, 2022b).

considering life expectancy, human development literacy, and child mortality (United Nations, 2019). See the contrast in Table 1.

Health inequalities and low education increase the risk of disability (World Health Organization, 2000). A National Health Survey pointed out, in 2019, that 17.2 million people over 2 years of age (8.4% of population¹) live with some type of disability (IBGE, 2022b). The survey also showed the disability distribution (Table 2). In addition, 59% of people with disabilities belong to adults between 15 and 64 years old. Only 28.3% of people with disabilities of working age (14 years of age or older) were in the labor force; more than half of people with disabilities (61.1%) do not have schooling or have incomplete primary education.

In this article, we define intellectual and developmental disabilities (I/DD) as a wide variety of neurodevelopmental conditions present in the prenatal period or at an early age that have made the course of the individual's physical, intellectual, and/or emotional development (Santos et al., 2020). Among the total of 2.5 million Brazilians² with I/DD (50% female), there is a concentration of 24.8% of those aged 60 years and over, while in the group aged 2–59 years this result corresponded to 5.1% (IBGE, 2022b).

The present article is a descriptive study concerning the organization of healthcare for individuals with I/DD in Brazil, which aims to characterize the Care Network for Person with Disabilities (in Portuguese, *Rede de Cuidados à Pessoa com Deficiências*), as well as its challenges in the country.

BRAZIL'S GENERAL HEALTH SYSTEM

Healthcare Services for the general population are offered by the National Health System or Sistema Único de Saúde (SUS, in Portuguese). According to the Ministry of Health (Brazil, 2000), the SUS is a nationwide public health system that serves the entire population free of charge, regardless of their socioeconomic status. Such a system works based on three principles, namely: (i) universality (service for all); (ii) comprehensiveness (based on needs); and (iii) equity (reduction of inequalities). The SUS is the result of a process of social and democratic mobilization instituted in 1990, consolidating the prerogatives of the Brazilian Constitution (Law no. 8.080, 1990).

Currently, the SUS is organized and functioning at levels of care for the general population, namely: (i) Primary or Basic Care; (ii) Secondary or Specialized Care; and (iii) Emergency Hospital Care (Ministry of Health, Brazil, 2010). Primary Healthcare demands vacancies and is the gateway to the care network, including managing vacancies for people with disabilities in specialized care. According to the National Health Survey (2019), there are more than 42 000 basic health units with 44 000 Family Health teams and 1229 Primary Care teams.

Within the levels of healthcare, the SUS is also structured in networks (Figure 1) with specific demands, based on the guidelines of the Health Metrics Network and World Health Organization (2008). The Healthcare

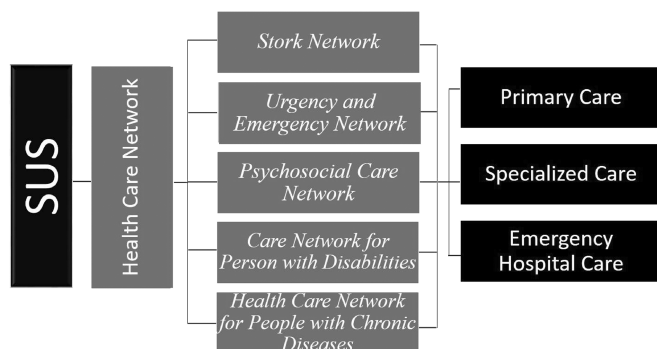


FIGURE 1 SUS Organization in Brazil. Created by the authors. Adapted from Gléria (2019). SUS, Unified Health System.

Networks were structured with the guidelines established by the Ministry of Health, through Ordinance No. 4279/10. They are: (i) Stork Network; (ii) Urgency and Emergency Network; (iii) Psychosocial Care Network; (iv) Care Network for Person with Disabilities (focus of this article); and (v) Healthcare Network for People with Chronic Diseases. For details on the networks, see the document of Ministry of Health (2014).

The health financing system in Brazil occurs through public and private sources. Such funding is supported by contributions and taxes collected at the federal, state, and municipal levels. According to the Federal Constitution, municipalities allocate 15% of what is collected to health actions. For state governments, this percentage is 12%. Finally, the Federal Government accounts for what was spent in the previous year, plus the nominal variation of the GDP. Then, this variation is added to the expenses from the previous year to define the value of the minimum investment for the year (Ministry of Health, Brazil, 2013). In this sense, if a region has a less representative GDP compared to others, less resources may be allocated to health in that region, reflecting in fewer hospitals, fewer medical doctors, less equipment, and so on.

Within the SUS, the Care Network for People with Disabilities (CNPd) is responsible for assisting individuals with I/DD as it follows.

THE CNPD AND ITS ACTORS

Established in Brazil in 2012, the CNPD aims to expand and improve care for people with temporary or permanent forms of disability due to progressive or chronic conditions, offering intermittent or continuous treatment within the SUS. The focus of this network is on the organization and comprehensive healthcare for people with hearing, physical, intellectual, ostomy or multiple disabilities (Ministry of Health, 2012).

The network also develops actions for the prevention and early identification of disorders during prenatal, perinatal, and postnatal phases, and throughout childhood, adolescence, and adulthood (Oliveira & Garcia, 2017). People with I/DD or other neurodevelopmental disorders (Autism; Down Syndrome; Cerebral Palsy, etc.) undertake mental and physical health, including dental care in the same health services as the general population. However, habilitation and rehabilitation services, such as physiotherapy, occupational therapy, speech therapy, among others, are offered in Specialized Rehabilitation Center (CER, Centro Especializado em Reabilitação, in Portuguese).

The CNPD has the following components, as shown in Figure 2. It accounts for 296 Specialized Rehabilitation Center and 48 Orthopedic Workshops, distributed throughout Brazil (Ministry of Health, 2023).

As for hospital and urgent and emergency care, the components of the CNPD are articulated with each other, in order to guarantee comprehensive care and regulated access to each point of care and/or support services, observing the inherent and indispensable specificities to guarantee equity in the care of these users, namely: (i) accessibility; (ii) communication; (iii) clinical management; (iv) measures to prevent functional loss, to reduce the rate of functional loss and/or to improve or recover function; and (v) measures of compensation for lost function and maintenance of current function (Ministry of Health, 2012).

The Care Network is articulated with the Family Health Strategy for home care (Pires et al., 2013). This service allows people with I/DD in serious health conditions (walking difficulties or bedridden) to receive care in their own homes. The team includes a medical doctor, a nursing technician, and a nurse.

The International Classification of Functioning (WHO, 2001) provides an integrative model for both the individual attributes and their social environment. The Modified Brazilian Functioning Index (IFBr-M, in Portuguese, Índice de Funcionalidade Brasileiro—Modificado) is the core disability measure accounting for body functions, the independence level, the degree of participation and the barriers present in each social sphere (Franzoi et al., 2013). Nevertheless, the medical diagnosis targeting social security, judicial and assistance is based on the International Classification of Diseases (WHO, 2019).

Many specialized institutions offer assistance and healthcare in habilitation and rehabilitation of neurodevelopmental disorders, such as Association of Parents and Friends of the Exceptional Children (APAE), Society for the Rehabilitation and Reintegration of the Disabled (SORRI), Association for Assistance to Disabled Children

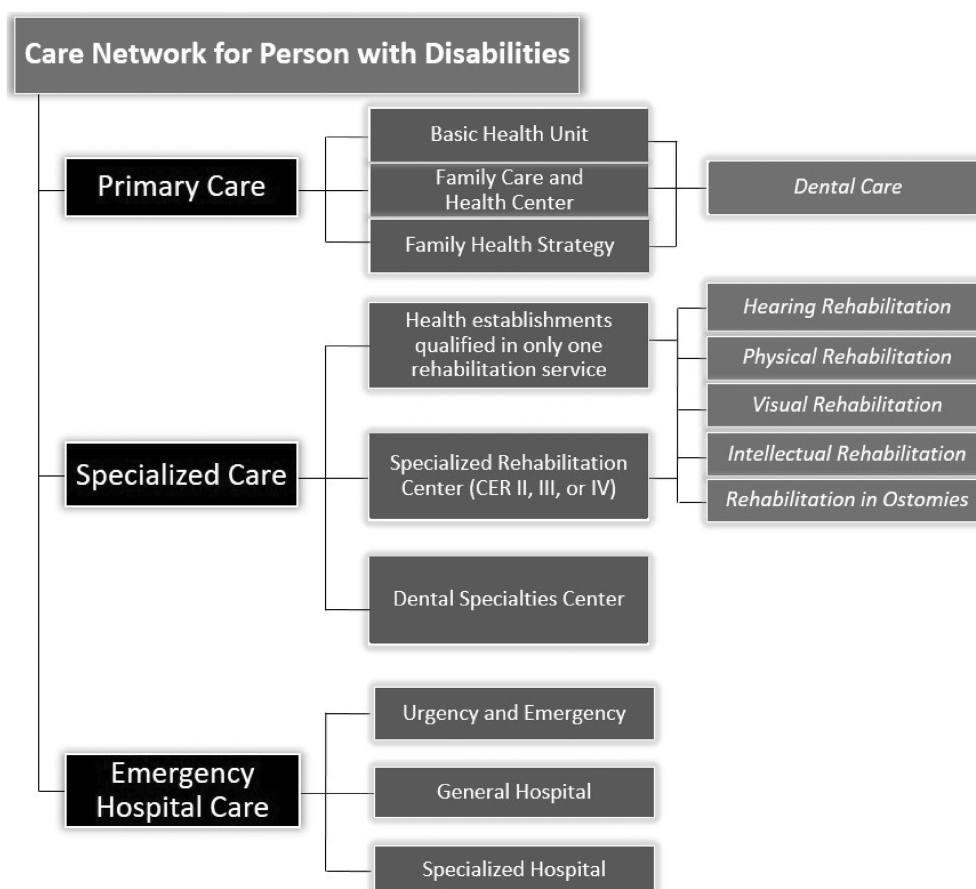


FIGURE 2 Components of the care network for person with disabilities. Adapted from Dourado et al. (2022). CER, Centro Especializado em Reabilitação, in Portuguese.

(AACD), as well as Lucy Montoro and Sarah Kubtschek Networks. In general, in such institutions, healthcare focuses on rehabilitation through a multidisciplinary team (Medical Doctors, Nurses, Nutritionists, Psychologists, Physiotherapists, Occupational Therapists, Speech Therapists and Social Worker).

The Brazilian Law of Inclusion determines continued training for those professionals, depending on the area of expertise. For instance, knowledge in Augmentative and Alternative Communication for the Speech-Language Pathologist is expected or suggested (Elsahar et al., 2019) while Applied Behavior Analysis (Lovaas, 1987) or Neuropsychology (Stringer, 2011), as well as Sensory Integration (Ayres, 1972), are recommended for psychologists. However, the quality of assistance to people with I/DD might vary considering the team expertise, resources available and the protocols in place at the service (Lopes et al., 2021). For instance, centers and hospitals affiliated to public universities are more likely to adopt up-to-date international standards, and gradually such practices will expand to remote areas.

Germani et al. (2022) highlight the need to promote internships, residency, and projects for undergraduate

students to interact with people with I/DD early in their career development. Scientific initiation and university extension projects represent a relevant strategy to guarantee comprehensive, equitable, and universal care, in addition to the practice of future health professionals with this public (Costa, 2015).

BRAZILIAN LEGISLATION ON HEALTHCARE FOR PEOPLE WITH I/DD

Many laws have contributed to the current model of healthcare available for people with I/DD nowadays (see Figure 3). Brazilian Constitution (Brazil, 1988), a supreme law fruit of the country's democratization process, determines the competence of States and Municipalities to "[...] take care of public health and assistance, the protection and guarantee of people with disabilities."

Subsequent legislation aimed to ensure priority and adequate care for different types of disabilities. The National Health Policy for People with Disabilities is the guideline for the promotion of quality of life,



FIGURE 3 Framework of Brazilian health legislation for people with I/DD. Created by the authors. I/DD, intellectual and developmental disabilities.

comprehensive care, prevention of disabilities, expansion and strengthening of information mechanisms, organization and operation of care services for people with disabilities and training of human resources.

In addition, the National Plan for the Rights of Persons with Disabilities—“Living without Limits” was instituted, as well as the CNPD in the SUS. The National Health Promotion Policy brought accurate information regarding healthcare for people with I/DD (Interdonato & Greguol, 2012). These changes were implemented in response to the International Convention on the Rights of Persons with Disabilities—CRPD (United Nations, 2006). The CRPD was signed in Brazil on March 30, 2007. Its ratification happened in 2009 through Federal Decree.

To date, the most important advance is the Statute of Person with Disabilities (Brazil, 2015), aiming for more dignity in their daily life, emphasizing the access to society in a plural way. It is supported by the Permanent Accessibility Commission, that monitors and guides adaptations of the living environment and intervenes with regard to materials, assistive technologies, and digital inclusion.

Regarding the legal aspects, the Statute makes clear the right to supported decision-making, which is essential for people with disabilities to be able to carry out acts of civil life safely, to the extent of their disabilities, but with due legal certainty.

HEALTH-RELATED CHALLENGES AND DISPARITIES TO PEOPLE WITH I/DD IN BRAZIL

Even though having the same health rights, people with I/DD face challenges compared to the general population (Campos et al., 2015; Dubow et al., 2018; Santos et al., 2021; Wiegand & de Meirelles, 2020). Such challenges stem from health-related disparities compared with the general population.

A key barrier encountered by people with I/DD is diagnosis access due to a number of factors, such as mechanization of work, lack of professional preparation and large number of appointments performed by a professional in the public SUS (Bazon et al., 2004). Consequently, there is poor interaction between some healthcare professionals, people with I/DD and their families. In addition, the wait for an efficient service in the SUS can last for months or years, especially when people with I/DD need tests such as the karyotype (Bazon et al., 2004). Recently, the National Council of Justice published a report in 2021 that points to an increase in lawsuits by families due to the waiting time.

Another challenge is the lack of effectively inclusive medical services (Castro et al., 2011). Attitudinal (prejudiced actions), geographic (long distances), and architectural (inadequate buildings) barriers also disfavor healthcare for people with I/DD (Lopes et al., 2021). Such disparities emerge from social and cultural directions (socioeconomic status; place of residence; age; race/ethnicity; gender, conception of disability), mainly comparing access to healthcare for people with I/DD and the general population (Krahn et al., 2006; Sampaio, 2018). These disparities corroborate the global report on health equity for people with disabilities, recently published by the WHO (2022).

Krahn et al. (2015) depict a scenario that is also common in Brazil for those facing economic barriers (Sampaio, 2018): i) greater probability of not receiving necessary care; ii) little access to adapted transport; iii) difficulties related to waiting at the service locations (e.g., low tolerance of challenging behavior; and iv) lack of a caregiver available to accompany them in medical appointments.

Another barrier is communication with health professionals. Although municipalities have encouraged the training of health professionals (e.g., in Sign Language) to care for the deaf community (de Sousa &

TABLE 3 National studies about healthcare for people with I/DD in Brazil.

Title of publication	Type of publication	Topic	Reference
Healthcare for people with disabilities in the Unified Health System in Brazil: A scoping review	Scientific article	Evidence on the experience of people with disabilities in Brazil with respect to the National Health Policy for People with Disabilities	da Cunha et al. (2022)
Gynecological care for women with intellectual disabilities: A Brazilian study	Scientific article	Challenges in the gynecological care and management of patients with intellectual disability by gynecologists	Leão et al. (2022)
A national accessibility audit of primary healthcare facilities in Brazil: Are people with disabilities being denied their right to health?	Scientific article	Findings from the first national assessment of the accessibility of primary healthcare facilities, undertaken in Brazil	Pinto et al. (2021)
Perceptions on the care network for disabled people in a health region	Scientific article	Analysis of the context, relations and perceptions of different actors involved in the network implementation for disabled people	Dubow et al. (2018)
Healthcare for people with intellectual disabilities: Analysis of policy instruments for basic care in Cruz das Almas-Bahia	Dissertation	Analysis of explicit and implicit speeches of healthcare professionals and families about care provision to people with ID in the context of the SUS	Sampaio (2018)

Note: Created by the authors.

Abbreviations: I/DD, intellectual and developmental disabilities; SUS, Unified Health System.

Almeida, 2017), people with I/DD (with Autism or Down Syndrome without verbal communication) continue to be misunderstood. This is particularly relevant while interpreting neurobehavioral components that might be typical of their diagnosis (e.g., echolalia or stereotypy) or related to a life circumstance (e.g., grief), which not rarely leads to non-clinically justified prescriptions (Prasher et al., 2021; Santos et al., 2018) particularly to avoid specific behavioral management.

IN-DEPTH READING SUGGESTIONS

Table 3 presents some articles and a dissertation to expand the understanding of healthcare for people with I/DD in Brazil. The inclusion criteria of these Brazilian productions in this table are based on the relationship between the SUS, healthcare for people with I/DD, and recent publications.

DISCUSSION

To the best of our knowledge, this is the first article to characterize the CNPD, and particularly to describe the organization of the healthcare system for people with

I/DD in Brazil. Despite our efforts to provide an accurate portrait, this is not an exhaustive account of strengths and weaknesses of the system and respective networks. Info comes from varied sources, data may be inconsistently available in terms of structure, regions, details, and chronological aspects. Equivalent literature from other nations remains scarce, at least, until the present Special Issue which hopefully will allow future comparative studies.

While Brazil has promoted legislation in favor of the health of people with I/DD and other disabilities, the obstacle is its applicability. Primary care services have a high demand for medical and dental consultations and a long waiting list for laboratory tests. In the case of imaging exams, if elective, the waiting list may exceed 1 year (Bazon et al., 2004). Although increasing the number of vacancies for care and appointments, by increasing the number of health professionals and respective facilities would be the natural course to address the issue, the rise of conservative governments in the last decade reduced investments in health and education, worsening the scenario.

Specialized Rehabilitation Centers (secondary care) encounter similar challenges which are maximized by the fact that resources are not evenly distributed. Brazilian regions receive investment in health

proportional to the respective economical resources generated (IBGE, 2022a). After the first referral, the people with I/DD will be properly assessed by an interdisciplinary team and then derived to all kinds of special care needed. However, there is a delay between primary care and the specialist referrals (Bazon et al., 2004). As highlighted by the National Council of Justice report (2021), the increase in specialized rehabilitation units can supply or at least reduce the waiting list for specialized care for people with I/DD. Moreover, there is a need for substantial investment on professional training to allow the multiprofessional team to deliver person-centered care for people with I/DD (Costa, 2015; Germani et al., 2022).

In this descriptive article, we also identified health disparities between people with I/DD and their counterparts such as late diagnosis, late access to treatment, stigma, geographical barriers, scarcity of friendly environments and precarious communication with healthcare professionals (Lopes et al., 2021; Sampaio, 2018). Poverty seems to be the cradle of anticipated health inequities. Finally, based on the challenges and disparities presented, it is necessary to ensure the principle of equity in healthcare for people with I/DD, pointed out in the global report on health equity for people with disabilities (WHO, 2022).

This article is just the starting point of the debate. Future research may identify aspects that improve medical and healthcare for people with I/DD in Brazil. The struggle for the realization of the rights to healthcare with quality and equity for people with disabilities in the country and the world continues. Such a challenge is imposed!

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CONFLICT OF INTEREST STATEMENT

Authors declare that they have no conflicts of interest.

ETHICS STATEMENT

As per policy, research that does not involve human or animal participants, their material or data are not required to seek ethical approval. However, despite the exemption, this theoretical work was conducted with integrity, namely, honesty, transparency, and trustworthiness.

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ENDNOTES

- ¹ The percentage of 8.4% corresponds to the share of people who have some type of disability.
- ² The 1.2% (2.5 million) corresponds to the total number of people with ID in the Brazilian population and not the population with some type of disability.

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Norwegian perspectives on health care for people with intellectual and developmental disabilities

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Abstract

The Norwegian health care system is built on individual rights and the principles of universal access, decentralization, and free choice of provider. Norway has universal health coverage, funded primarily by general taxes and by payroll contributions shared by employers and employees. Local authorities at the municipal level organize and finance primary health care services according to local demand and within national frameworks. Habilitation services are offered both in the primary health care and as a part of the specialist health services. They offer both inpatient and outpatient services for people with intellectual/developmental disabilities (IDD). National guidelines, known as *Good health and care services for people with IDD*, have recently (2021) been launched after various reports over the years of serious breaches and challenges in the health and care services provided to people with IDD.

KEYWORDS

healthcare, intellectual disability, norway, services

INTRODUCTION

The population of Norway is 5.4 million. As with most other countries, the exact number of people in Norway with intellectual and developmental disabilities (IDD) is unknown. Most people with mild IDD are not in the municipal health and care files, and therefore not registered. What we do know is that approximately 20 000 people over 16 years of age who receive public health and care services are registered with IDD.¹

The Nordic nations—Finland, Iceland, Norway, Denmark and Sweden—have similar approaches to health and social welfare, the so-called Nordic social welfare model based on social democratic ideology. The Nordic model ensures that all citizens are entitled to basic social security

and services. The welfare policy is wide-ranging and includes social security, social services, health, education and training, housing, employment, etc. Social and health services are financed by taxes, and the Nordic countries have a large public sector (Nordic Health & Welfare Statistics, 2022).

The public health system in Norway has three administrative levels. In addition to the government's overall responsibility, primary health care is organized by the municipalities, and specialist health services, including all hospitals, are organized by four regional health trusts. Norwegian policy and legislation will be covered later in the paper.

SERVICE DESIGN AND PRACTICE

Primary health care

Authorities at the municipal level organize and finance the primary health care services for the local population, with

Abbreviations: CRPD, convention on the rights of persons with disabilities; GP, general practitioner; IDD, intellectual/developmental disabilities; PHD, primary healthcare teams.

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the goal of providing sufficient services as close as possible to where people live. Norway has a well-functioning public health and social system, but private providers are also available. The Norwegian health care system is characterized by universality. The system is built on individual rights and the principles of universal access, decentralization, and free choice of provider. It is financed by taxation, together with employer contributions and deductible. Local authorities at the municipal level organize and finance primary health care services according to local demand and within national frameworks. They are divided in primary health care, care services and rehabilitation and social services. Primary and preventive healthcare, habilitation, rehabilitation and nursing care are organized locally, often in cooperation with the counties. All municipalities must statutorily guarantee access to publicly funded physiotherapy services. Municipalities are also responsible for providing long-term care for the population. The public health services in Norway are nearly cost-free, but there is a small fee, deductible, for consultations, tests and medical examinations. The deductible, including primary and specialized health services, medical expenses and travel expenses, has an upper annual limit, which is approximately 270€ in 2023. Expenses above this amount are covered by the state. Changes may appear based on political priorities, but the principle of publicly financed health care is fundamental. Income disparities in Norway regarding salary are relatively even, but it appears that it is becoming increasingly more common to apply deductible instead of all welfare services being financed by taxes on various services (Nordic Health & Welfare Statistics, 2022).

Based on political governance, in 1991 a national reform was implemented that affected the lives of people with IDD. All institutions for housing this population in Norway were discontinued, and their residents were relocated in decentralized dwellings in the municipalities. The aim of the reform was for people with IDD to be included into society and to receive health and care services in the same way that other inhabitants do. Today, most people with IDD live in community settings where they rent or own their apartments and receive services there. A small minority of people with IDD (circa 25%) own their housing, in contrast to the general population where most (circa 80%) own their home.² The apartments are often gathered together, and some are linked to a municipal service centre with support personnel. Support personnel can be a combination of social educators, registered nurses, and health personnel/care providers with or without professional training.

All of Norway's inhabitants are entitled to a general practitioner (GP)/ family doctor. For all medical services, the first contact is through the GP (except for emergencies). When specialized health services are needed, the GP refers patients to the specialist health services, which include

habilitation in the specialist health services (described below under the specialist health services), medical specialties, and hospital services for further assessment or treatment. GPs do visit patients in their homes, but more often, patients visit the GP's office as needed.

Statutory right to an individual plan

Everyone who needs long-term and coordinated health and care services has the right (by law) to have a written, individualized plan. The municipality has the primary responsibility for developing an individual plan when the person with IDD receives services from both the municipality and the specialist health service, which participates in the planning when involved. One of the service providers must be appointed as coordinator and must ensure the necessary follow-up of the individual user. The coordinator must also ensure coordination of the service offered and that progress is made in the work with the individual plan. People with IDD should be included in the development of their own individual plan when possible. The main purpose of the plan is to ensure user participation and to increase the possibility to influence their own lives. An individual plan should strengthen the interaction between service providers, users, and their next of kin. It is important to note that such a plan does not per se grant access to services. The right to services arise from an individual decision pursuant to the Administrative Procedures Act and the Health and Care Services Act.

Unfortunately, an evaluation conducted by the Norwegian Directorate of Health (2017–2019) revealed that the statutory requirement of the individual plan and the coordinator does not work as intended; few people with IDD were found to have a functional individual plan. The exact number is not known, but in 2021, a report from Municipal patient and user registries (Directorate of Health, 2021) indicated that only 10% of service recipients living at home with a need for habilitation and rehabilitation had an effective individual plan.

Primary healthcare teams

To improve health care for people with IDD, an ongoing project called Primary Healthcare Teams (PHTs) is being piloted at 13 GP practices distributed in eight municipalities in Norway (2018–2023). A PHT consists of doctors, nurses, and administrative assistants. The doctor and the nurse make home visits to people with IDD to assess and follow up their health needs, and they perform video consultations with care providers and patients. Evaluations thus far have found that PHTs lead to improved

co-operation between GPs, patients, next of kin and care providers in the community.³

Structured interdisciplinary follow-up teams

Another ongoing project in six municipalities is called Structured Interdisciplinary Follow-up Teams. The target group is people with highly significant and complex needs, regardless of age and diagnosis. The goal is early identification of needs, and a new electronic tool for risk mapping will be tested in the pilot. Initially, it will be tested with 67 GPs and later will be used in hospitals as well.⁴

Free dental care

People in Norway who are registered with IDD have access to free dental care services throughout their lives, unlike the general adult population, which typically must pay the full cost of dental service. However, more than one-third of those with IDD in a recent study experienced poor dental health despite frequent dental check-ups (Olsen et al., 2022).

Specialist health services

The specialist health service includes all hospitals in Norway. The hospitals offer the general population, inclusive of individuals with IDD, specialized treatment, and the state owns the public hospitals, which are organized in four regional health trusts.

Habilitation

When the institutions for people with IDD were discontinued in 1991, habilitation services in the specialist health services were established in each of the 19 counties in Norway to support those with IDD with specialized physical and mental health care. The goal is to increase their quality of life. The habilitation services are organized under the hospitals and health trusts in the specialist health services. They offer both inpatient and outpatient services for this population. The services cooperate closely with the primary health services, and it is the GP, who refers patients to habilitation services. The service is divided into two sections: children and youth habilitation (0–18 years) and adult habilitation (18 years and older). People with IDD may be examined or treated in the premises of the habilitation service or in the hospitals. This will depend on which service will provide the best

outcome for the user in the regional health trust to which he or she belongs.

The habilitation services have interdisciplinary staff that include professions such as medical specialists, psychologists, physiotherapists, occupational therapists, social educators and other health specialties. Staff in the habilitation services may vary in professions in the various health region,⁵ but they are specialized in communication and cooperation with people with IDD. The habilitation units' obligations cover health assessment, treatment, medical check-ups and health training for people with IDD. During the COVID-19 pandemic, they also offered video consultations with care providers and patients.

All national habilitation services for the adult population of people with IDD were evaluated in a recent report.⁶ The report pointed out three main objectives based on feedback from the local communities: (1) supervision related to challenging behavior, (2) diagnostic assessments, and (3) supervision related to restraint measures. Similar evaluations have been undertaken within the childhood habilitation services⁷ with quite different targets for the services, namely (1) building robust local and regional habilitation services, (2) establishing national resource networks, (3) developing adapted service pathways for children with major needs, and (4) developing national standards for children with cerebral palsy. The gap between children and adults in regard to habilitation services may result in both discontinuation of service and separate user groups for these services. The gap illustrates how important it is for these two services to collaborate to achieve the goal of a comprehensive health service for people with IDD throughout their life course.

The Norwegian government actively encourages municipalities to focus more on prevention to limit the use of expensive hospital services. Patients are transferred to the municipal health service as quickly as medically and professionally advisable in order to be treated and followed up as close as possible to where they live or in their homes.

The specialist health services offer several national and regional treatment services that provide health care to patients in need of highly specialized medical treatment. The national and regional treatment services are located in various regions of Norway, and their purpose is to ensure that people with IDD have more equitable access to high-quality patient treatment; secondary purposes include greater cost-effectiveness and improved health education. National advisory services have been established to develop and raise the quality of the services provided and to deliver services as safely as possible to people with IDD. This is accomplished by building and disseminating knowledge and best practices/experience nationwide as long as there is a need for these services.

Several national advisory services are available for service providers. Examples include the Norwegian National Advisory Unit on Mental Health in Intellectual Disabilities, the Norwegian National Centre for Ageing and Health (Ageing and Health) and the National Institute on Intellectual Disability and Community (NAKU). In addition, there are several regional centres, for example, the Regional section of psychiatry, developmental disabilities/autism at Oslo University Hospital. Both children and youth habilitation and adult habilitation services are regional resources for people with IDD.

In addition, Norway has numerous organizations whose focus is working for people with IDD. A significant contributor is the SOR foundation whose purpose is to support research, professional development and communication in all areas that can serve to increase understanding about developmental disabilities and lead to more effective methods for prevention, treatment and training.

Hospitalization among adults with IDD

Some years ago, a research study investigated hospitalization among adults with IDD and compared it to the general population in Norway. The survey was based on data from national registries for the period 2008–2011. The results showed that the proportion of people hospitalized each year was almost the same among adults with IDD as that of the adult general population. However, in contrast to the distribution in the general population, people with IDD in the younger age groups (35–69 years) were hospitalized more frequently, and those in the oldest groups (69–89 years) were hospitalized less frequently. The most common reasons for hospital admission for people with IDDS were injury, poisoning and certain other consequences of external causes (S00–T98, ICD-10), diseases of the circulatory system (I00–I99, ICD-10), and diseases of the digestive system (K00–K93, ICD-10). Cancer and musculoskeletal diseases are notably less often the cause of hospital admission for people with IDD compared with the general population. (Skorpen et al., 2016).

Pharmaceutical drugs

Pharmaceutical drug use among people with IDD was also investigated in Norway recently. The findings indicate that adults with IDD use more drugs than the general population, with anticonvulsant and psycholeptic drugs being those most commonly used. Middle-aged and older adults (50+) with IDD use lower rates of several drugs than the general population, and this pattern was particularly clear

for drugs targeting the cardiovascular system. Cardiovascular diseases are among the leading causes of death for individuals with IDD (Hove et al., 2019).

Psychiatry services

Norwegian psychiatry services are organized in the same way as somatic health services. As previously mentioned, health authorities have a goal of providing services as close as possible to where people live. Thus, most people receive help from the psychiatry services through the decentralized system of District Psychiatric Centres and a few from specialist psychiatry in the specialist health service. Those with IDD generally receive mental health care services through the habilitation services or from specialized mental health services, such as the Regional section of psychiatry, developmental disabilities/autism at Oslo University Hospital.

It is important to add that people with IDD receive services in Norway's hospitals on equal terms with the rest of the population. Moreover, those with mild IDD often arrive for visits at the health service alone, but most are accompanied by a service provider from their housing situation. If a patient needs a companion who is a care provider from their housing during a hospital stay, the cost to cover this must be arranged through an agreement between the hospital and the municipal health administration.

Restraint measures

Norway has implemented a restrictive practice in regard to the use of restraint measures in caring for people with IDD who may display harmful behaviors. Chapter 9 of the *The Health and Care Services Act* applies to interventions intended to prevent or respond to a harmful incident, and such interventions may include seclusion and physical or mechanical restraint. It also divides restraint measures into emergency situations or planned interventions where restraint measures are included as part of an individual care plan. A worrisome trend has been a significant increase in the use of planned/statutory interventions (Søndenaa et al., 2015). However, the prevalence of restrictive practices cannot be compared to those of other nations that do not have similar regulations in place or national statistics that aim to monitor such practices.

Acute/emergency medical care

Emergency care for people with IDD in Norway is the same as that for the general population. When an

emergency occurs outside the GP's normal office hours, one must contact the out-of-hours medical service. All municipalities in Norway offer an out-of-hours medical service for immediate medical assistance 24 h a day. This service can be reached by calling a six-digit number (116117) at no cost to contact the local out-of-hours medical centre. In the event of an immediate risk to life, one must call the emergency medical dispatch centre (113) for the most rapid response and assistance.

POLICY DEVELOPMENTS

The processes of social inclusion, user participation and user empowerment are based on a relational perspective of the individual's reduced functional ability. This relational perspective is called the gap model, wherein the person experiences limitations because of the "gap" between her or his reduced ability to function and the demands of the society. This model is combined with the obligations and objectives of the Convention on the Rights of Persons with IDD, CRPD, the UN report on sustainable development, and the new national guidelines.

During the last decade, several noteworthy policy changes have taken place in Norway. As one of the last countries to do so, Norway ratified the CRPD in 2013. Recent national reports have focused on the limitation of self-determination; reduced legal security; a lack of coordination of welfare services; a lack of goal management, coordination and implementation; and a lack of statistics and documentation in the services. In one report,⁸ the Governmental Ministry of Children and Families proposed eight targets that needed enhancements in order to secure the fulfillment of human rights for people with IDD to be equal to those of other citizens. These targets included the right to (1) self-determination, (2) an inclusive and equal education, (3) more-accessible workplaces, (4) good health and care, (5) have their own homes, (6) expertise and knowledge through care, (7) coordinated services, and (8) targeted management.

Further, in 2017, the Norwegian Board of Health Supervision inspected the municipal health and social services for people with IDD in 57 municipalities. Service violations were found in 45 municipalities (83%), some of them serious. The service *personal assistance* was inadequate. There was no plan for training; the services provision was not systematic and documentation was incomplete; and staff lacked information about the clients they were expected to help and about the tasks they should carry out. The report described a limitation, lack or exclusion in participation from the service users point of view concerning decisions about the services, and relatives were uninformed regarding

what they needed to do in order to address the interests of the persons with IDD.⁹ There are some challenges linked to the missing formal competence in these services, with only 30% of the staff having a relevant bachelor degree (Ellingsen et al., 2020).

National guidelines, known as *Good health and care services for people with IDD*,¹⁰ were developed after various reports over the years of serious violations and challenges in the health and care services provided to people with IDD. The purpose of the guidelines is to help the services to categorize, prioritize and systematize their efforts to improve the quality of services for people with IDD and their families in line with their own situations, wishes and needs. The guidelines describe best practices in important areas such as life transitions, habilitation, health care follow-up and cooperation between the services and the families. The Directorate of Health has also provided a set of guidelines; however, the document also demands that all Norwegian municipalities maintain high standards for a variety of services in order to ensure the equality of the welfare of people with IDD. Further, it addresses the requirements that the primary services must accomplish. Problems with such mandated obligations include the absence of support needed from specialist services, local priorities, and limited professional and financial resources.

Official reports have documented the limitations of services for people with IDD. One recent report from the Equality and Anti-Discrimination Ombud refers to *The right to an independent living and to be part of society* (2022). This report assessed how services for people with developmental disabilities can either promote or weaken their opportunities to live independently as members of society. It further studied how the services can enable those with IDD to have an influence on major life decisions and their own everyday lives. The report was based on 117 complaints directed to Norway's national welfare authorities. It concluded that there was a lack of documentation showing that the person with an IDD and his or her guardian or next of kin had been allowed to participate in the design of the service. Individual adaptation was mostly about functional assessments and was seldom related to the goals and wishes of the person with needs for services. This report indicates that the delivery of quality health-care for people with IDD in Norway has yet to be realized for some members of this population.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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ENDNOTES

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- ² The developmentally disabled housing situation 2021, https://samforsk.no/uploads/files/Utviklingshemmetes_bosituasjon_web.pdf.
- ³ Norwegian Directorate of Health, <https://www.helsedirektoratet.no>.
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ORIGINAL ARTICLE



Perspectives on healthcare for people with intellectual disabilities in Poland

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Abstract

This paper presents current information on policy developments, service design, best practices, and approaches to empower the users of health and medical care services for people with intellectual disabilities in Poland. Polish regulations allow systemic support to be provided for all people with disabilities. However, Polish patients with intellectual disability (PwID) and their caregivers face many barriers. Although a key obstacle is the lack of a standard definition that approaches disability in an interdisciplinary way, PwID are also more likely to experience difficulties in personal communication in medical settings and less likely to encounter specialists prepared to work with this group. There is also a need to pay greater attention to the expectations of PwID. To facilitate a holistic approach to diagnosis and therapy, there needs to be coordination between different specialists, including medical staff, paramedics, psychologists, and teachers. Providing personal communication training for medical personnel, as well as developing dedicated procedures for PwID in primary health care, clinics and hospitals, will improve equal access to health and health literacy for all in Poland. Even so, it is important to respect the autonomy of PwID and the commitment of caregivers.

KEYWORDS

health and medical care, people with intellectual disabilities, Poland

INTRODUCTION

The Republic of Poland (RP) is the largest country in central and eastern Europe, with over 38 mln inhabitants (Główny Urząd Statystyczny, 2022). According to Article 68 of the 1997 Constitution of RP, all citizens have the right to health protection and equal access to health services (Konstytucja Rzeczypospolitej Polskiej, 1997). The health system itself is regulated by the Parliament, The Ministry of Health, and the Council of Ministers. The payer function remains centralized within *The National Health Fund* (Narodowy Fundusz Zdrowia, 2022) and

health system is financed from public funds, such as obligatory social health insurance (SHI), state and territorial budgets, and private resources. The Polish government is obliged to assure free health care for children, pregnant women, people with disabilities (PwDs), and the elderly population. All employees, those registered as unemployed, spouses, students under 26, farmers, pensioners, and retirees are automatically covered by SHI. If a child has a severe disability, there is no age limit for registration in SHI by family members (Kieliszek et al., 2019; Sowada et al., 2019). In addition to the public healthcare system, patients can also use private health services.



Around 10% of the Polish population is affected by legal disability (confirmed by a certificate issued by an authorized body) and 23% by biological disability, which means feeling of limitation of efficiency in performing basic activities (Główny Urząd Statystyczny, 2019). In the quarter of 2022, 17 784 Polish citizens under 16 years of age and 86 118 of those aged 16 and over were diagnosed with intellectual disabilities (ID) (Biuro Pełnomocnika Rządu do Spraw Osób Niepełnosprawnych, 2022). The experience of practitioners allows us to assume that these data are not representative.

The degree of impairment, limitations and support that a person needs in everyday life are reviewed by *The District/Municipality Disability Assessment Boards* (Powiatowy/Miejski Zespół ds. Orzekania o Niepełnosprawności). Their tasks include recognizing and adjudicating on disability, referring to appropriate facilities, and determining indications regarding the need to inter alia provide orthopedic equipment or ensure constant care. Disability is evaluated as severe, moderate or mild; this status is recorded in a legal document, which serves as the basis for entitlement to benefits, reliefs and entitlements (Ustawa o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych, 1997). People incapable of living independently are entitled to receive a regular social pension, awarded by *The Social Insurance Institution* (Zakład Ubezpieczeń Społecznych) (Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych and Zakład Ubezpieczeń Społecznych, 2022).

Providing support for PwDs is one of the key activities of the government in the field of social policy. In 2018, *The Solidarity Fund* (Fundusz Solidarnościowy) was established, which provides social, professional, health, and financial support (Ustawa o Solidarnościowym Funduszu Wsparcia Osób Niepełnosprawnych, 2018). It also provides personal assistance services to enable PwDs to lead a more independent and active life (Ministerstwo Rodziny i Polityki Społecznej, 2022a).

The most well-known institutionalized initiative is *The State Fund for the Rehabilitation of Persons with Disability* (Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych), established in 1991. Its funds are allocated, inter alia, for the elimination of architectural and personal communication barriers, and supplying individuals with rehabilitation and orthopedic equipment and aids (Ustawa o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych, 1997).

This paper presents current information on policy developments, service design, best practices, and approaches to user empowerment in health and medical care services for people with ID (PwID) in Poland.

MATERIALS AND METHODS

The present paper analyses the current demographic, social and legal data concerning persons with disability (PwDs) in Poland, with a particular focus on PwID. It also reviews the relevant legal acts via the Polish Government Legislation Centre webpage. The demographic characteristics of the Polish population were mainly based on data from Statistics Poland and Eurostat. Data on the forms of treatment and rehabilitation in Poland were obtained from books, articles and web pages of *The Government Plenipotentiary for Disabled People* (Biuro Pełnomocnika Rządu do Spraw Osób Niepełnosprawnych) and institutions providing care to PwID in Poland. The review covered PubMed, Google Scholar, Scopus, Web of Science, and CEJSH databases using the following keywords: English: “intellectual disability”, “developmental disability”, “mental retardation”, “neurodevelopmental disorders”, “health care”, and “medical care”. The search was also performed with the analogous Polish terms. The data were collected from May to July 2022 by a team consisting of a specialist in public health, a clinical psychologist, and experts working with PwID.

RESULTS

Legislation and policy regarding people with ID, status of United Nations convention on disability, availability of specific health policy

No documentation focusing purely on Polish governmental policy toward PwID appears to exist. However, following demographic trends and signing the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) by Polish government in 2007, than its ratification by The President of RP in September 2012, interest in the needs and rights of PwDs has grown (Ministerstwo Rodziny i Polityki Społecznej, 2012).

In 2018 the government appointed a national program called *The Accessibility Plus* (Dostępność Plus); this is the first systematic resolution in Poland intended to improve the accessibility of public spaces, products and services, and implementing legal, institutional, and financial solutions to meet the specific needs of vulnerable groups (Ministerstwo Inwestycji i Rozwoju, 2018). In 2022, the Accessibility Standards for Primary Care, Accessibility Standards for Hospitals and savoir-vivre rules for medical facilities were developed as a part of this program (Ministerstwo Zdrowia, 2022a).

The current program, *The Strategy on People with Disability* (Strategia na Rzecz Osób z Niepełnosprawnościami),

taking into account the principles of CRPD, was established in 2021. It includes an update of a comprehensive, horizontal, cross-sectoral public policy approach to support PwDs with independent living, social inclusion, and professional development. This strategy contains general eight action areas, including one focused on health; it requires the provision of health care for PwDs, together with access to health services, programs meeting their specific healthcare requirements, medical rehabilitation, and optimizing quality of functioning (Biuro Pełnomocnika Rządu do Spraw Osób Niepełnosprawnych, 2021).

Finally, an aim of the National Health Program for the years 2021–2025 is not only to increase the number of years lived in good health but also to reduce social inequalities regarding healthcare. All implemented strategies in healthcare aim to ensure accessibility, following the concept of universal design, defined in Article 2 of the CRPD (Ministerstwo Zdrowia, 2021).

Lifespan healthcare transitions among PwID

Early intervention among children with ID

Since 2016, the “*For Life*” program has provided adequate healthcare services for women and families during pregnancy, childbirth, and postpartum, with particular emphasis on complicated pregnancies and obstetric failures. A child with severe and irreversible intellectual impairment or an incurable life-threatening disease formed during the prenatal period or childbirth is provided with adequate health care, care coordination, and rehabilitation services (Ministerstwo Rodziny i Polityki Społecznej, 2016).

Additionally, *Early Intervention Centres* (Ośrodki Wczesnej Interwencji) are health care facilities for children with delayed or disharmonious psychomotor development and those with ID aged 0 until the start of school. The centers provide multi-specialist and comprehensive medical, psychological, physiotherapeutic and speech therapy diagnoses, multi-profile programs for improving intellectual, motor, social, and emotional functioning, as well as periodic evaluations and individual therapeutic interventions for the child. To take part, a referral from a doctor is necessary; such assistance is free of charge (Wrona, 2020).

In addition to visiting a pediatrician, the parent should report to a public *Psychological-Educational Counseling Center* (Poradnie Psychologiczno Pedagogiczne). Such assistance is voluntary and free of charge, and no referral is required. These centers perform evaluations according to education regulations.

In such cases, pupils with disabilities are recognized as requiring individual learning programs and working methods (Piotrowicz, 2014).

Access to public health services by children and adults with ID

All PwID have the equal right and access to public healthcare services, including those associated with disease prevention, diagnosis and treatment, and the prevention of disability development (Ministerstwo Zdrowia, 2022b).

Those up to the age of 18, with central nervous system disorders, can receive outpatient physiotherapy at a specialist center or day wards following referral once per calendar year, during 120 treatment days with up to five treatments per day. The duration of rehabilitation can be extended for medical reasons. Children with severe disabilities can continue rehabilitation until the age of 25 after presenting a certificate confirming a need for special education or for rehabilitation-and-education classes (Narodowy Fundusz Zdrowia, 2022).

In Poland, some PwID who are 13 years of age or older have total or partial incapacitation. Therefore, decisions regarding their treatment are made by their legal representatives or factual guardians. However, if the patient has sufficient understanding but objects to medical treatment, or if the guardian refuses treatment, permission must be obtained from the guardianship court to undertake treatment (Ustawa o zawodach lekarza i lekarza denty, 1996). For years, efforts have been underway in Poland to abolish incapacitation and replace it with personal or assisted forms of supported decision-making (Głab, 2022; Helsinki Foundation for Human Rights, 2022; Radlińska, 2017).

All Polish PwDs enjoy specific rights and rules when using health care. All patients with a severe degree of disability are entitled to priority treatment for public health care, including primary care services (primary care doctor, nurse, and midwife), hospital services, outpatient specialist care, rehabilitation, and pharmaceutical services. As such, they can obtain medical support during the same day of reporting to outpatient specialist care or, if this is not possible, within the next seven working days. In addition, they do not need a referral to take advantage of outpatient specialist services, except for expensive diagnostic tests like magnetic resonance imaging and therapeutic rehabilitation. Furthermore, PwDs obtain co-financing for ordered medical products. People with a severe or moderate degree of disability are entitled to general anesthesia at the dentist and the use of composite light-curing materials for fillings (Rzecznik Praw Pacjenta, 2022).

TABLE 1 Recent studies concerning healthcare for patients with intellectual and disability (PwIDs) in Poland.

	Title of publication	Type of publication	Topic	Reference
1	Services for patients with intellectual disability and mental health problems in Poland	Article	Services for PwID and mental health problems	Krysta, K., Krysta, J., Szczegielniak, A., & Krzystanek, M. 2019. <i>Psychiatria Danubina</i> , 31(Suppl 3), 534–542. https://hrcak.srce.hr/264168
2	Poradnik szkoła specjalna promująca zdrowie [Handbook for the health promotion in special school]	Monography	Principles and recommendations for health promotion in schools for children and young people with ID	Wojnarowska- Soldan M, Wojnarowska B, Danielewicz D. Ośrodek Rozwoju Edukacji. Warszawa 2020. https://www.kuratorium.waw.pl/pl/dyrektor-i-nauczyciel/szkoly-promujace-zdrowi/15069,Nowy-podrecznik-dla-szkol-specjalnych-Szkola-Specjalna-Promujaca-Zdrowie.html
3	Pacjent z niepełnosprawnością intelektualną w systemie ochrony zdrowia—co możemy zrobić lepiej [Patient with intellectual disability in health care—what can we do better]	Article	Recommendations about cooperation with PwID in health care.	Libura M. 2019. <i>Med. Prakt.</i> , 2019; 1: 142–145. Pacjent z niepełnosprawnością intelektualną w systemie ochrony zdrowia – co możemy zrobić lepiej. https://www.mp.pl/komunikacja/lekarz-pacjent/trudny_pacjent/202230,pacjent-z-niepelnosprawnoscia-intelektualna-w-systemie-ochrony-zdrowia

Some Polish PwIDs live in residential homes for children, youths, or adults with ID. Although they do not perform medical services themselves, they are obliged to provide health services to residents and to cover any flat fees and partial payments up to the price limits specified for universal insurance. They must also provide rooms for medical emergencies and rehabilitation (Rozporządzenie Ministra Pracy i Polityki Społecznej w sprawie domów pomocy społecznej, 2012).

RECENT STUDIES CONCERNING HEALTHCARE FOR PwIDs IN POLAND

Table 1 presents the most relevant documents pertaining to Polish health care. Krysta et al. (2019) discuss the implementation of national policy and human rights in relation to people with mental and ID, as well as the associated legal problems, diagnostic and therapeutic issues, including access to health services. Wojnarowska- Soldan et al. (2020) describe the principles of health promotion and education for children and young people with ID in Polish schools and provide recommendations; all activities are currently performed by

school nurses and teachers, and aim to give pupils the opportunity to reflect on their health behaviors and motivate them to develop positive ones. In turn, Libura (2019) reflects on the problems arising when communicating with patients with ID, difficulties in medical diagnosis and care and attitudes toward this group in a medical setting; the paper also offers recommendations on improving quality of care, while paying special attention to promotion of communication training for medical staff, commitment of caregivers and patient autonomy.

DISCUSSION

Polish patients with ID and their caregivers face many barriers in access to health and medical care and a key obstacle is the lack of a standard definition that approaches disability in an interdisciplinary way. Instead, the legal acts of three ministries engaged in care for PwIDs (Ministry of Health, Ministry of Social Policy and Family, Ministry for Education and Science) employ different definitions and highlight different aspects. As such, there is a need to unify the general concept of disability expressed in administrative law to include

features of the holistic model complemented by the cultural context. This would improve cooperation between specialists in different fields of medical care, social support and education and enable planning interventions tailored to the specific needs of PwIDs (Ministerstwo Edukacji Narodowej, 2017).

Further limitations arise from inadequate organizational solutions in the medical care system and individual health care facilities. Although PwIDs are much more likely to suffer health problems than the general population, they are also more likely to encounter difficulties in personal communication, a lack of knowledge about their disorders, especially in rare genetic diseases, and a lack of specialists prepared to work with PwIDs (Libura, 2019). Although the risk of mental disorders among Polish PwID is up to three times higher than in the general population, they lack adequate diagnostic tools and specialists (Rękosiewicz, 2018). No special category for ID Psychiatry exists in Polish psychiatric training, and no inpatient or outpatient psychiatric services are provided typically for PwIDs (Casanova Dias et al., 2020; Krysta et al., 2019). However, the current reform underway in the pediatric mental health system, together with changes in the mode of training specialists, should improve the quality of care. The reform includes three reference levels, adjusted to the needs of the child: *Centres for Community Psychological and Psychotherapeutic Care for Children and Teenagers* (Ośrodki Środowiskowej Opieki Psychologicznej i Psychoterapeutycznej dla Dzieci i Młodzieży), outpatient and day-open *Mental Health Centres for Children and Teenagers* (Centra Zdrowia Psychicznego dla Dzieci i Młodzieży), and finally *Medical Centres for Highly Specialized 24-h Psychiatric Care* (Ośrodek Wysokospecjalistycznej Całodobowej Opieki Psychiatrycznej) where stationary services are provided. This reorganization aims to facilitate early access to assistance and reduce the risk of hospitalization by strengthening specialized community care (Ministerstwo Zdrowia, 2022c).

So far, other healthcare workers, e.g., medical doctors, nurses or paramedics, are also not sufficiently prepared to work with PwID. Research on the sexual health of PwID highlighted that although students of Polish medical schools expressed positive attitudes toward their sexual needs and behaviors, level of education may be insufficient for preparing them for their professional duties (Parchomiuk & Trojanowska, 2018).

Surveys of Polish children and adults with ID indicate a need for improvement in dental care, dissemination of prophylaxis, and education on caring for oral health (Borysewicz-Lewicka et al., 2018; Fernandez Rojas et al., 2016; Gerreth et al., 2017; Hendzel & Wolańska, 2016; Mach, 2018). Moreover, the needs of women with ID have been recognized (Plagens-Rotman et al., 2021); the Polish Society of Gynecologists and Obstetricians has issued

recommendations on care for young women with physical and ID (Drosdzol-Cop et al., 2020).

While the COVID-19 pandemic has exacerbated the difficulties faced by PwID in accessing primary and specialized health care, it has also highlighted the need to pay greater attention to the needs of vulnerable populations, and to provide more suitable remote services (Parchomiuk, 2021). The development of e-health is an urgent challenge for healthcare. Despite their great potential in providing healthcare for PwID (Krysta et al., 2017, 2021; Sahaj, 2021; Selick et al., 2021), little has been written about the utilization of modern technologies and telemedicine in this group in Poland. The only set of published recommendations regarding preparing a child with ID for an online visit concerned telepsychiatry during COVID-19 pandemic (Krefft, 2020). However, an example of good practice can be seen in a school of childbirth in Wrocław providing a service to women with mild degree of ID, which worked online during the COVID-19 pandemic (Olszewska, 2020).

The Polish government has just prepared legislation to reduce the abovementioned limitations. *The Strategy on People with Disability* provides an opportunity to implement systematic and structural changes in different areas. Concerning the health of PwID, attention should be paid to developing and coordinating personalized, people-centered health care. For this, it is necessary to construct a framework ensuring coherence between health policy support system and institutions dealing with the issue of ID. Most PwID require the support of a third party in their dealings with health (Libura, 2019). As such, there is a need for greater coordination between the different levels of health care, education, and social support initiatives for PwID, as well as with caregivers and specialists. The first step to solve this problem is the fact that the government is currently following a deinstitutionalization policy intended to allow PwDs to stay in their place of residence, i.e., family homes, assisted, training or supported housing, as long as possible (Ministerstwo Rodziny i Polityki Społecznej, 2022b).

Some government and non-government institutions are working to improve the situation of Polish PwID. *The Office of the Government Plenipotentiary for People with Disabilities* plays a crucial role in advocacy by developing programs improving the social and professional living conditions of PwDs, initiating and coordinating activities aimed at limiting the effects of disability and removing barriers preventing PwDs from functioning in society, as well as encouraging cooperation with non-governmental organizations. Moreover, government and local administrations are cooperating with various non-profit religious and non-religious social organizations, as well as with employers and PwDs (Chrzanowska, 2015; Zarębska, 2008).

The oldest non-profit organization dedicated to PwID in Poland and Eastern Europe is the Polish Association for People with Intellectual Disability (Polskie Stowarzyszenie na rzecz Osób z Niepełnosprawnością Intelektualną), established in the 1960s by parents of children with ID. This organization supports legislative work and social campaigns, develops the idea of self-advocacy among PwIDs and creates directions for developing medical and psychosocial rehabilitation in cooperation with specialists, parents, and PwID. It also produces and distributes leaflets, books, videos, or other educational materials (including health education) adapted to the needs of PwID (Polskie Stowarzyszenie na rzecz Osób z Niepełnosprawnością Intelektualną, 2022).

In conclusion, although Polish regulations allow systemic support to be provided for PwIDs, they need to pay greater consideration to the needs of PwID. A holistic approach to diagnosis and therapy requires coordination between different specialists, such as medical staff, paramedics, psychologists, and teachers. Providing personal communication trainings for medical personnel, as well as developing dedicated procedures for PwID in primary health care, clinics and hospitals, will improve equal access to health and health literacy for all. Two key components in the process are respect for the autonomy of patients and for the knowledge and commitment of caregivers.

CONFLICT OF INTEREST STATEMENT

There are no potential conflicts of interests.

ETHICS STATEMENT

We confirm that all the research meets ethical standards, guidelines and legal requirements.

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