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SPECIAL ISSUE ARTICLE



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).

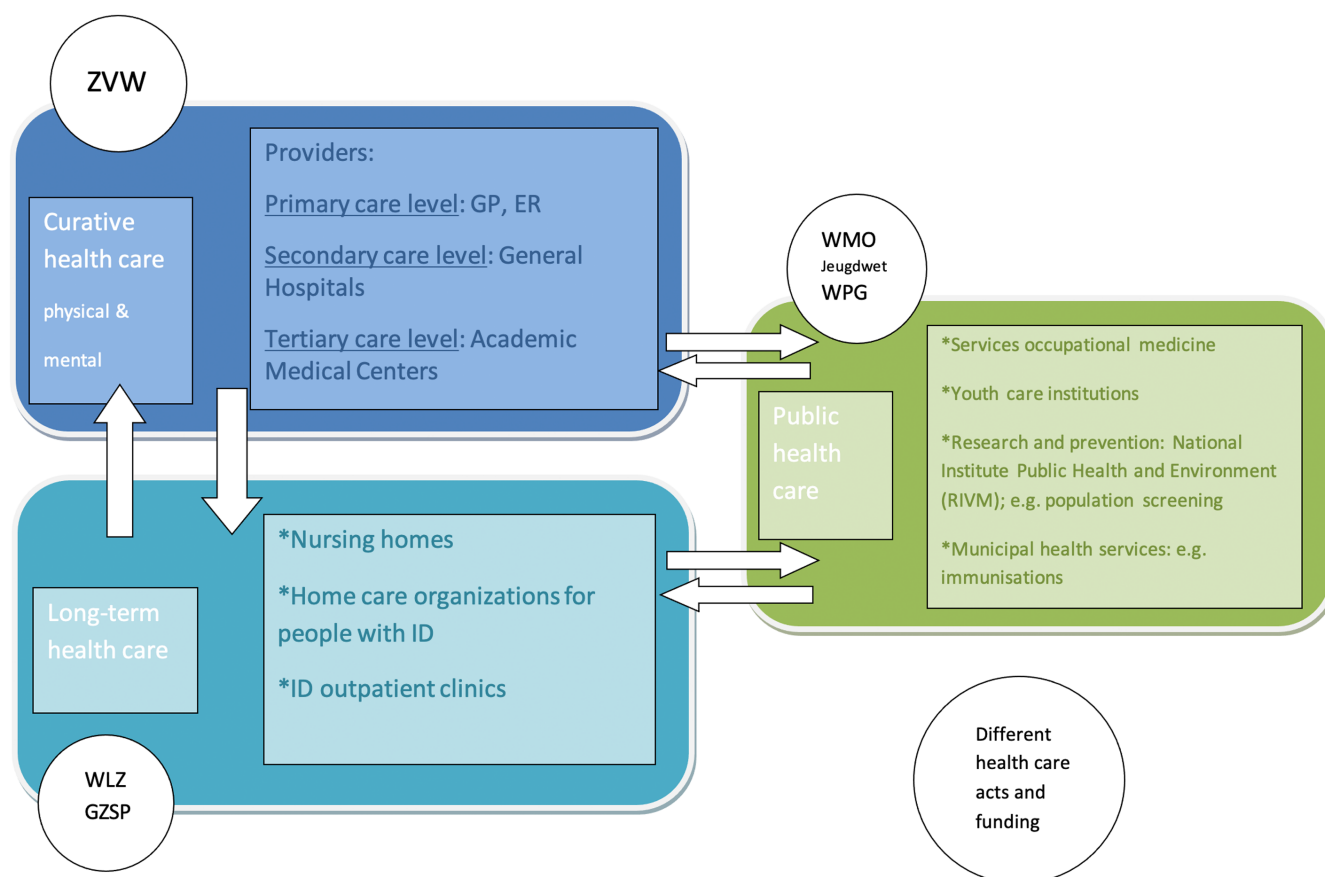


FIGURE 1 The Dutch healthcare system: three interconnected segments, governed, and funded by their own laws.

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 | Cuypers 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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