Towards equitable healthcare for people with intellectual disabilities

The role of specialized medical ID expertise

Marian Breuer

Towards equitable healthcare for people with intellectual disabilities: the role of specialized medical ID expertise

Context, content, and perspectives

Marian Breuer

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Chapter 1

General introduction

General introduction

People with intellectual disabilities (ID) can have complex medical care needs. Professionals are not always equipped to address these needs, leading to health inequities. A few months after starting this thesis, the COVID-19 pandemic took place, and this further illustrated the health inequities people with ID experience to me. During the pandemic, people with ID experienced higher morbidity and mortality rates compared with the general population [1, 2]. Measures that were put in place to protect people, such as shielding and isolation, resulted in increasing health problems and problems with access to adequate healthcare [3-5]. People with ID and the care sector for this population experienced a lack of public acknowledgement and recognition for the impact of the pandemic and healthcare systems worldwide experienced challenges in addressing the needs of people with ID [3-5]. For me, the COVID-19 pandemic underscored the urgent need for healthcare systems to prioritize the improvement of medical care for people with ID. I tried to look into the public health responses to COVID-19 across the world, with the goal of learning from the approaches of other countries. However, this proved to be extremely difficult, because healthcare for people with ID is organized differently across countries. Without knowledge on the context of organization of medical care in which the responses were developed, I could not obtain a good understanding. Even the concepts of health and medical care are used in different ways and interchangeably. The lack of international conferences and platforms to share knowledge and experiences contributed to this. With this thesis, I hope to contribute to a better understanding of medical care for people with ID to facilitate international learning.

The complex medical care needs of people with ID

People with ID experience significant limitations in both intellectual functioning and adaptive behaviour as expressed in lower conceptual (e.g., language, money), social (e.g., interpersonal skills), and practical (e.g., activities of daily living) skills [6]. These limitations originate before the age of 22. People with ID are a heterogenous group with different expressions and impact of the disability. People with ID are characterized by an IQ below 75. Exact prevalence numbers of people with ID are lacking because of under-recognition and under-registration of ID, and the lack of a consistent definition of ID [7, 8]. For example, differences in included age groups and case definitions lead to variation in who is counted. It is estimated that people with ID account for approximately 1–3% of the global population [7, 9-11]. The Netherlands has no central registration system for people with ID, but estimated numbers of people with ID range between 187,000 and 440,000, depending on definitions and methodologies [7, 12]. A recent Dutch study estimated ID prevalence at 1.45% [7]. An additional 1.1 million people (6.4% of the Dutch population) have characteristics of ID, such as low IQ (<85) and problems in adaptive functioning, but are not always diagnosed with ID [7, 13].

Besides limitations in intellectual functioning and adaptive behaviour, people with ID have different medical care needs compared with the general population. ID-related medical care needs can complicate medical care provision, because medical care professionals do not always feel equipped to manage these needs, leading to health inequity. For instance, people with ID may experience difficulties in recognizing and expressing signs of disease, may present symptoms in an atypical way, and may experience communication difficulties. This can influence how disease symptoms are understood and communicated. Furthermore, having an ID can entail different morbidity patterns, comorbidity, and syndrome-related health problems [14, 15]. Consequently, people with ID are often misunderstood and their diseases misdiagnosed or undiagnosed [16, 17]. The complex medical care needs of people with ID in combination with healthcare systems that are not equipped to meet these needs lead to a greater burden of multimorbidity, higher levels of undetected and unmanaged health problems, health inequities, and higher rates of avoidable deaths in people with ID [14, 16, 18-20].

International medical care arrangements for people with ID

The optimal way to organize the medical care for people with ID has been under debate for decades [21-24]. One of the central questions in these debates is “Who is responsible for providing medical care for people with ID?” [23]. Countries have developed diverse approaches to providing their medical care, ranging from enhancing mainstream medical care to developing specialized services [21, 22, 25-29]. Despite these different approaches, medical care for people with ID remains suboptimal [16].

Understanding how medical care is organized across countries allows for collaboration and knowledge exchange between healthcare professionals, researchers, and policymakers. This collaboration and exchange, at the national as well as at the international level, facilitates the development of improved healthcare systems worldwide [30]. Additionally, this understanding is crucial for collaborative advocacy efforts and for raising awareness about the needs of people with ID, and provides possible opportunities for joint research projects, shared resources, and cross-country initiatives [31]. The need for international collaboration and learning was highlighted during the COVID-19 pandemic [4, 32]. The disadvantaged position of people with ID and the different international responses to the pandemic created a need for the international exchange of experiences about people with ID and their health and care during the pandemic to facilitate international learning [5, 33, 34]. However, this exchange was hampered by the lack of an international overview of the organization of medical care for people with ID [35]. Without this overview, comparing and contrasting practices across countries becomes challenging, because what works in one country may not be applicable to another country.

Medical care provision for people with ID in the Netherlands

Reforms in Dutch long-term care policy in 2015 resulted in people with ID increasingly living in community settings, supported by the Social support act (Wet maatschappelijke ondersteuning). As a result, general practitioners (GPs) became more responsible for providing medical care for people with ID living in the community. People with ID living in residential care facilities receive medical care from physicians working in these facilities. This most often concerns specialized ID physicians and GPs.

In 2000, the medical specialization ID physician was established in the Netherlands. ID physicians have a three-year postgraduate training in all the aspects of specialized medical care for people with ID. The current 250 registered ID physicians work in residential care settings and outpatient clinics, where services are available for people with ID who do not live in long-term care settings [36]. GPs or medical specialists can refer a patient to one of the 73 outpatient services spread throughout the Netherlands [37]. Figure 1.1 provides an overview of the organization of medical care for people with ID in the Netherlands.

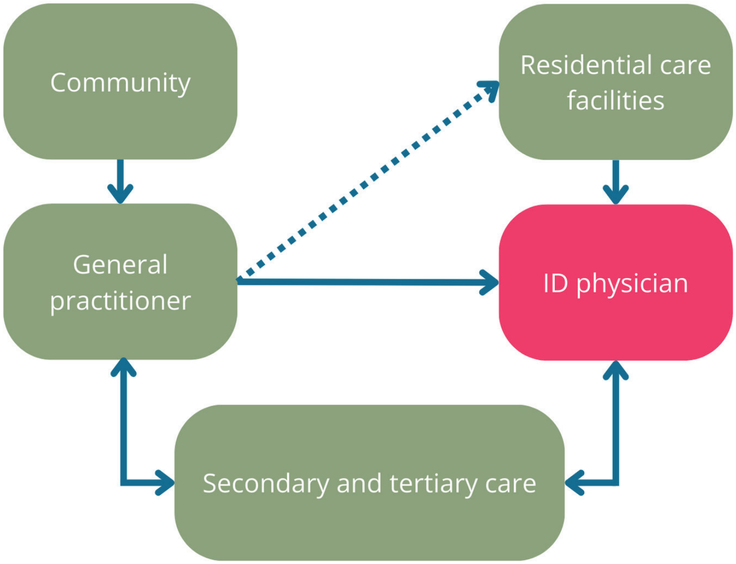

Figure 1.1 Simplified overview of the organization of medical care for people with ID in the Netherlands

Figure 1.2 shows that the GP usually provides general medical care for people with ID and the ID physician provides ID-specific medical care. While both medical care professionals are complementary to each other, the overlap in provided care causes ambiguity around responsibilities. The ID physician has expertise in the field of specific health and communication problems of people with ID but is not trained as a GP. In contrast, GPs are not trained to provide ID-specific medical care. Therefore, optimal medical care for people with ID requires collaboration between the GP and the ID physician. Guidelines for this collaboration have been compiled [38], but responsibilities remain unclear [39]. This calls for more knowledge on the role of specialized medical ID expertise in the medical care for people with ID [21, 22, 40]. The Dutch context with dedicated ID physicians offers the opportunity to learn about the content and role of specialized medical care for people with ID that they provide.

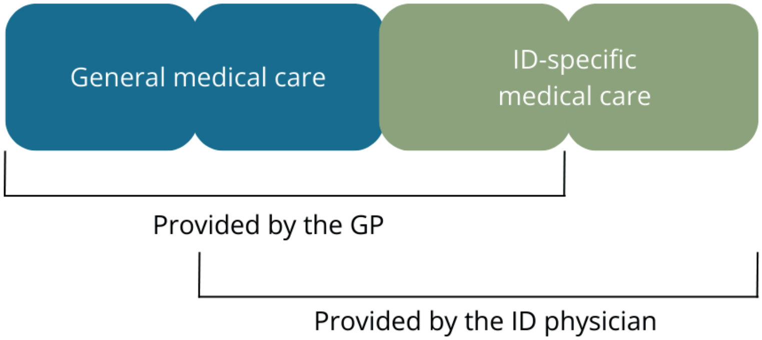

Figure 1.2 The relation and overlap between medical care provided by the GP and by the ID physician

A step towards equitable healthcare for people with ID

The United Convention on the Rights of People with Disabilities (UNCRPD), adopted in 2006, represents a watershed in the global recognition of the rights of persons with disabilities, including people with ID [41]. By signing and ratifying the UNCRPD, 188 countries and states made a global commitment towards an equitable world in which people with disabilities have the right to the same range, quality, and standard of free or affordable healthcare as provided to other persons as defined in Article 25 [41]. The UNCRPD marks a significant step towards inclusive healthcare for people with ID, but challenges persist in its implementation [42-45]. Currently, the experienced problems in the medical care for people with ID challenge the rights as acknowledged in the UNCRPD.

The COVID-19 pandemic illustrated that steps need to be taken to achieve equitable medical care for people with ID. Specialized expertise in the medical care for people with ID has been widely suggested as a solution to the health inequities they experience [16, 21, 46-48]. However, evidence on the role of this expertise is lacking and international cooperation is limited. International exchange and learning are hampered by differences in the organization of medical care for people with ID across countries and a lack of insight in the international organization of this care. A first step towards inclusive medical care for people with ID is to improve our understanding of current medical care provision for this population and current challenges and best practices across countries.

Aims of this thesis

This thesis aims to investigate the role of specialized expertise in the medical care for people with ID and identify opportunities to improve this care. More specifically, the sub-aims of this thesis are:

1. Explore international professionals' views on the medical care for people with ID.
2. Gain insight into the similarities and differences in the organization of healthcare for people with ID across countries.
3. Investigate the content of medical care provided in a Dutch outpatient ID practice in terms of referral reasons, problems presented, and disciplines involved.
4. Explore patients' and their support persons' perspectives on a medical consultation with a specialized ID physician at an outpatient ID practice.

Research setting

This research was conducted within the setting of the academic collaborative Stronger on your own feet (*Sterker op eigen benen*), a collaboration for practice-oriented research between the Radboud university medical centre and six care provider services for people with ID [49]. Stronger on your own feet aims to improve the (daily) healthcare for people with ID through scientific research on health inequalities and disadvantages, the use of the expertise of ID physicians in practice, and education of healthcare professionals and medical students. The close collaboration and continuous exchange of knowledge and experience between researchers, healthcare professionals, and educators accomplished in academic collaboratives leads to new insights and a better understanding of the complexity of the medical care for people with ID which benefits this thesis research. In addition, this research's results can more quickly be disseminated to interested parties through the academic collaborative.

The research team and advisory board consisted of people with different backgrounds, adding to a broad interpretation of findings. The research team consisted of health researchers and physician researchers. To enhance the connection with practice, an advisory board provided feedback on the research design, reflected on research results, and advised on the dissemination of results. The advisory board, consisting of ID physicians working in care organizations or at an outpatient ID practice, a (former) GP, a paediatrician, a parent of a person with ID, a senior policy advisor, a specialist nurse, and a knowledge and science coordinator, met twice a year for three years to discuss progress and implications of the research. A co-researcher with ID assisted in various phases of the research. When necessary, additional external advisors (i.e., a research methodologist, co-researchers with ID, and researchers experienced with international studies) were consulted to improve the quality and rigour of our research.

Methodological considerations

A wide range of medical care professionals, patients and relatives/representatives, and settings were included in this thesis. A combination of concept mapping, international synthesis, retrospective cohort study, and semi-structured interviews was used. The combination of data from different perspectives, sources, and methods increases validity by providing different forms of triangulation [50]. This thesis applied data source triangulation by using different sources about the same topic, combining experts' and patients' perspectives on medical care for people with ID. Methods triangulation was used by the combined use of qualitative and quantitative methods in this thesis. Results from the concept mapping study informed the interview topic guide. Researcher triangulation was applied by the active involvement of members of the research team and the advisory board. Table 1.1 describes the methods and data sources for the research chapters of this thesis. Because the organization of medical care for people with ID differs between countries, an international perspective was applied. Three of the studies presented in this thesis (Chapters 2, 3, and 4) were performed during the COVID-19 pandemic. The impact of the COVID-19 pandemic on the research in this thesis' research is reflected on in Chapter 6. The questionnaire and study design of the interview study (Chapter 5) were developed with a co-researcher with an ID.

Table 1.1 Methods and data sources used in the research chapters of this thesis

Aim	Chapter	Method	Data source	Setting
1	2	Mixed methods – concept mapping	Experts (researchers and clinicians) on medical care for people with ID	International
2	3	Qualitative – content analysis	Experts (researchers) with knowledge on the organization of medical care for people with ID	International
3	4	Quantitative – retrospective cohort study	Administrative system – Routine data	The Netherlands – outpatient ID practice
4	5	Qualitative – semi-structured interviews	People with ID and their companions	The Netherlands – outpatient ID practice

Outline of this thesis

Chapter 2 describes a concept mapping study in which international views on the aspects of medical care for people with ID are explored. **Chapter 3** explores international similarities and differences in the organization of healthcare for people with ID, including the challenges and best practices. This chapter is part of a special edition for the Journal of Policy and Practice in Intellectual Disabilities, initiated and co-edited as part of this thesis. The special edition provides insight in the organization of healthcare for people with ID in 13 countries. Then, two studies focussing on specialized medical ID consultations in the Netherlands follow. **Chapter 4** explores the characteristics of specialized medical care for people with ID, highlighting the interplay between medical, psychological, and context-related problems. In **Chapter 5**, patients' and their support persons' experiences with, and expectations of, a medical consultation with a specialized ID physician at an outpatient ID practice are explored. **Chapter 6** provides a general discussion of the main findings as presented in this thesis and recommendations for research, policy, education, and practice.

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Chapter 2

Exploring views on medical care for people with intellectual disabilities: an international concept mapping study

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Abstract

Background Medical care for people with intellectual and developmental disabilities (IDD) is organized differently across the globe and interpretation of the concept of medical care for people with IDD may vary across countries. Existing models of medical care are not tailored to the specific medical care needs of people with IDD. This study aims to provide an improved understanding of which aspects constitute medical care for people with IDD by exploring how international researchers and practitioners describe this care, using concept mapping.

Methods Twenty-five experts (researchers and practitioners) on medical care for people with IDD from 17 countries submitted statements on medical care in their country in a brainstorming session, using an online concept mapping tool. Next, they sorted all collected statements and rated them on importance.

Results Participants generated statements that reflect current medical and health care practice, their ideas on good practice, and aspirations for future medical and health care for people with IDD. Based on the sorting of all statements, a concept map was formed, covering 13 aspects that characterize medical and health care for people with IDD across nations. The 13 aspects varied minimally in importance ratings and were grouped into five overarching conceptual themes: (i) active patient role, (ii) provider role, (iii) context of care, (iv) consequences of care for people with IDD, and (v) quality of care.

Conclusions The themes, clusters and statements identified through this explorative study provide additional content and context for the specific patient group of people with IDD to the dimensions of previous models of medical care.

Introduction

People with intellectual and developmental disabilities (IDD) experience health inequities, and poorer health outcomes compared to the general population [1–3]. Some of these inequities can be prevented by improving medical care. For example, medical care professionals find it difficult to treat patients with IDD because of atypical presentations of complaints, different morbidity patterns, and more comorbidity and syndrome-related disorders compared with the general population [4–7]. Furthermore, communication and effective information exchange between medical care professionals and others involved is often problematic [8].

Countries have developed diverse approaches to provide medical care for people with IDD, ranging from enhancing mainstream medical care to developing specialized services [9–12]. Consequently, the organization of medical care differs internationally [9, 13–15] which makes comparison of the organization of medical care for people with IDD difficult. However, the diversity in approaches provides the opportunity to identify good practices and facilitate international understanding and learning.

Investigating differences in the international organization of medical care for people with IDD is difficult because there seems to be no generally accepted definition of medical care in literature [16, 17]. What we consider medical care may depend on country-specific cultural interpretations and institutional legacies [13]. Furthermore, the concepts medical care and health care are often used interchangeably. Overall, it is generally understood that medical care is a subset of health care. Medical care focuses on the diagnosis and treatment of an illness or injury of a person who needs medical attention, while health care focuses more broadly on promoting, maintaining, restoring, and monitoring the health of the public.

Existing models or frameworks of medical care are often focused on a specific part of this care, for example measuring access to medical care or quality of medical care, rather than describing medical care as a whole [17, 18]. More importantly, these models do not take into account aspects relating to specific medical care needs of people with IDD. Therefore, this study aims to provide an improved understanding of aspects of medical care for people with IDD by exploring how researchers and professionals describe medical care for people with IDD through a concept mapping (CM) study.

Methods

Study design and procedures

CM, a mixed-methods participatory approach, was used [19]. The study consisted of nine steps, which will be explained in detail in the Data Collection and Analysis section and are summarized in Table 2.1. Steps 1, 2, 4, 5, 6, and 7 describe the common procedures for a CM study [18]. Groupwisdom™ software for CM (The Concept Systems ® groupwisdom™ (Build 2019.24.01) [Web-based Platform], 2020) was used for data collection and analysis steps. In addition to the traditional CM procedure, the researchers performed three additional analyses beyond the scope of the used software to provide more insight in the data. Firstly, a qualitative analysis of the types of raw statements (step 3) was performed to better understand and represent the collected data, because the common CM procedure does not analyse the raw statements and only focuses on the content of the statements. Secondly, an additional sensitivity analysis (step 8) was performed to investigate the robustness of the final concept map. Lastly, a qualitative interpretation of the final cluster map (step 9) was performed to look for underlying dimensions within the data beyond the scope of the used software.

Table 2.1 Phases, activities, and time schedule of data collection and analysis

Phase	**Activities**	**Result**
1. Preparation brainstorming phase	Develop and pilot focus prompts (M.B., J.N., E.B., K.V.A., G.L.) • Advice Skype sessions with 3 researchers with expertise on medical care for people with intellectual and developmental disabilities (IDD) • Pre-pilot among 3 ID physicians concerning focus prompt • Pilot study among 3 members of the IASSIDD Health SIRG Invite possible participants for the study (M.B., J.N., E.B., K.V.A., G.L.) • Create participant sampling plan • Create & send email invitation Make software ready to use (M.B., K.V.A.)	1 focus prompt
2. Brainstorming	25 participants create responses related to the focus prompt	92 raw statements
3. Qualitative analysis of raw statements	Qualitative analysis of 92 raw statements that were generated from the 25 participants, according to the following steps (M.B., J.N., H.T.): • Researchers individually analyze the 92 responses looking for underlying dimensions • Researchers compare their analyses and collaboratively decide on the underlying dimensions	92 raw statements with underlying dimensions
4. Preparation organization phase	Statement synthesis using the following procedure (M.B., J.N., E.B., G.L.): • Split up statements containing >1 statement per sentence • Assign keywords to statements • Organize ideas based on keywords to bring overlapping statements together • Remove duplicates • Combine overlapping statements • Edit statements for clarity	92 raw statements reduced to a set of 79 unique statements
5. Organization	21 participants sort statements into piles of conceptually similar statements 18 participants rate statements on a 7-point Likert scale representing importance	79 statements individually sorted and rated

Phase	Activities	Result
6. Preparation analysis phase	Assessment of sorting and rating data using the following criteria (M.B., J.N., E.B.): • Number of sorted statements • Number of created piles • Number of labelled piles (participants could create piles without labelling them) • Consistency of statements within piles • Time spent on the sorting and rating Variation in rating (e.g., a participant's rating data was excluded if the same rating was provided to all statements)	Sorting data of 3 participants excluded from analysis
7. Concept mapping analysis	Analysis using the following methods (M.B., J.N., E.B., K.V.A., H.T., G.L.): A) *Multidimensional scaling*: create a point map based on the sorting data, visualizing the relationship and proximity of statements to one another B) *Hierarchical cluster analysis*: create a cluster map by grouping statements that are closest to one another: • Research team collaboratively decides on upper and lower limits of the number of clusters • Researchers individually review the list of statements that are merged when moving from the highest desired number of clusters to the lowest, by looking at the average bridging values of the clusters and statements and the conceptual consistency of statements within clusters • Researchers individually decide the cluster size that retains most useful detail (further merging leads to non-interpretable cluster map) • Researchers collaboratively choose final cluster size and names by examining cluster statements C) *Analyze importance ratings*: Calculate mean importance rate for statements and clusters	A) Point map B) Cluster map C) Ratings of statements and clusters
8. Additional sensitivity analysis	*Jackknife resampling method*: Estimate sensitivity of the concept map by comparing the original allocation of statements within clusters with the 18 distributions resulting from systematically omitting one participant from the sample	Sensitivity for sampling variation
9. Qualitative analysis of final cluster map	Qualitative interpretation on the final cluster map	5 themes

Participants

Sixty-four experts with research and/or clinical experience in medical care for people with IDD from a wide variety of countries were invited through email and asked to forward the invitation to potentially relevant participants (snowballing). Potential participants were identified from: (1) members of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health SIRG (special interest research group), (2) members of the IASSIDD Comparative policy and practice SIRG, (3) members of the GATE (Global Cooperation on Assistive Technology) community, (4) the network of the research team, and (5) international authors of research articles about the medical care for people with IDD. Eligible participants received study instructions and personal credentials to enter the Concept Systems Groupwisdom™ project website.

Thirty-five eligible experts responded positively and enrolled. Of these, 25 completed the brainstorming phase (71.4%), 21 completed the sorting phase (60%), and 18 completed the rating phase (51.4%). These numbers are in line with the recommendations for CM studies [20–22]. Table 2.2 describes the participant characteristics. The brainstorming phase yielded statements from 25 participants from 17 countries across six continents. On average, participants had 12 years of research experience and/or 17 years of clinical experience. Fifteen participants (43%) had experience in both research and clinical practice.

Table 2.2 Characteristics of participants

	Brainstorming (n=25)	Sorting (n=21)	Rating (n=18)
Continent of origin			
Europe	7	8	8
Asia	6	4	3
North America	5	3	2
South America	2	2	2
Oceania	3	2	2
Africa	2	2	1
Profession			
Medical doctor	9	7	7
Allied health professional	7	6	3
Registered nurse	3	3	3
Other	6	5	5
Years of clinical experience			
0-5	4	4	2
6-10	4	1	2
11-15	5	2	1
16-20	4	2	3
>20	8	12	10
Years of research experience			
0-5	6	4	3
6-10	6	2	2
11-15	8	9	9
16-20	2	2	1
>20	3	4	3
Sampling plan			
Network of research team	6	4	4
IASSIDD Special Interest Research Groups (SIRGs)	5	4	4
GATE community	2	3	2
Snowballing	11	10	8
Abstract books of previous congresses	1	0	0

Data collection and analysis

Preparation, data collection, and data analysis repeatedly alternated in nine consecutive steps (Table 2.1). Online data collection (step 2 and 5) took place from July 2020 through November 2020.

In step 1, the brainstorming phase was prepared by development of a recruitment plan and the focus prompt, which is a statement that participants respond to. During the (online) brainstorming phase (step 2), participants individually completed the following focus prompt in as many ways as possible: 'If you asked me to describe medical care for people with IDD in my country, I would say…'.

Participants were encouraged to think about medical care for people with IDD in its broadest sense and to consider different experiences or information relating to the focus prompt. They could enter an unlimited number of responses and could view all responses previously generated by different participants to stimulate their thinking process [19]. Demographics on country of residence, profession, years of research and/or clinical experience, and permission to be mentioned in the acknowledgements were obtained.

In step 3 (qualitative analysis of raw statements), three members of the research team individually read and coded each raw statement looking at different types of statements formulated by participants (rather than content related to medical care). Next, the researchers compared their analyses and collaboratively decided on three main types of statements (descriptive, normative, and prescriptive). Examples of these types of statements are provided in part 3.1 of the Results section.

In step 4 (preparation organization phase), four research team members prepared the final statement list for sorting and rating in step 5 by deleting duplicates, ensuring that each statement represented a unique idea, and light editing for clarity.

In step 5, the organization phase, statements were sorted by participants individually into groups of similarly themed statements and participants created descriptive labels for each group based on their unifying content. Next, participants individually rated each statement on a 7-point Likert scale based on its importance for the concept of medical care for people with IDD (1 = relatively unimportant; 7 = extremely important). To include as many different views as possible, participants did not have to finish the brainstorming phase to participate in the organization phase. The raw data from each step are available upon request.

In step 6 (preparation analysis phase), three participants' sorting data were excluded because of incompleteness (75% or fewer statements were sorted) or inaccurate sorting (misinterpretation of sorting assignment; e.g., application to one's own country).

In step 7 (concept mapping analysis), the sorting data of the remaining participants were used to create a similarity matrix showing how frequently participants sorted the same statements together. Multidimensional scaling, a technique that plots each statement as a point on a map, was used to create a 2D point map. Statements participants more frequently sorted in the same pile were plotted closer together on the point map, with spatial distance between each point representing how often statements were sorted together. To determine how well the 2D point map fitted the original sorting data, a stress value was calculated: a lower stress value suggests a better overall fit [23].

Hierarchical cluster analysis was used to combine spatially close statements into clusters. Bridging values (range 0–1), defined below, were calculated for all statements in the possible cluster solutions to help interpret the clusters and select the final cluster solution. A lower bridging value indicates that a statement was frequently sorted with statements adjacent to it. Cluster sizes and names were determined by the procedure recommended by Kane and Trochim (Table 2.1; step 7) [23]. The final cluster names were checked on language and connotation by one native English-speaking participant. Finally, participants' importance ratings were averaged for each statement and per cluster.

Sensitivity to sampling or robustness of the concept map (step 8) was investigated with a Jackknife procedure [24]. The Jackknife procedure entailed performing the CM analysis (step 7) 18 times on a sample of 17 participants, systematically omitting one participant (n-1). The 18 resulting concept maps were compared with the concept map resulting from the full data (including all 18 participants). The number of statements placed in a different cluster and the number of statements leaving and entering the cluster were calculated and it was assessed whether the statements within the cluster covered the same theme as in the original allocation using full data.

In step 9 (qualitative analysis of final cluster map), the final cluster map was scrutinized for overarching conceptual themes that could point towards an underlying dimension within the data beyond the scope of the used software.

Results

Qualitative analysis of raw statements (step 3)

Brainstorming (step 2) resulted in 92 raw statements (see Supplementary Table S2.1). The qualitative analysis of these raw statements indicated that there was a large diversity in how respondents interpreted the focus prompt; most raw statements were formulated negatively, and since statements were formulated from a specific country context, they could contradict each other. For example: "*Quality of services for people with IDD in hospitals or at GP's is usually low*" and "*Global standards for medical care are high. Therefore, most of the people with IDD get adequate treatment*". Although the focus prompt of this study guided towards descriptions of medical care, the collected statements show that participants did not always make a clear distinction between medical care and health care.

The qualitative analysis categorized raw statements into three main response types: 1) descriptive responses describing current medical care for people with IDD, for example: "*There are guidelines and tools to support health care providers for this group*", 2) normative opinions about what good medical care for people with IDD should entail, for example: "*Do any of us have a nurse following us around to pass medications when we are out of our home? Why is this normal for IDD population?*", and 3) prescriptive personal opinions and aspirations on what medical care for people with IDD should look like, for example: "*Improving communication between medical practitioners, allied health, and support organizations would improve medical care for people with IDD in my country*". Often, a statement combined two or more of these types. An example of a raw statement which contains descriptive as well as normative and prescriptive elements is: "*During Covid we find that we are essential workers. We are not paid that way (descriptive), how can we provide high quality care when we cannot attract high quality workers with the salary the state funds (prescriptive)? Our population suffers the most (normative)*".

Concept mapping analysis (step 7)

Point map

To prepare for the organization phase (step 5), the 92 raw statements were synthesized to 79 final statements (after removal of 13 duplicates) (see Supplementary Table S2.2). Participants sorted the statements in a minimum of four and a maximum of 18 clusters. Based on the sorting data (acquired in step 5), a point map was created, in which the proximity of the 79 statements to one another is projected on a 2D map (see Supplementary Figure S2.1).

Final concept map

The final concept map consists of 13 clusters. Figure 2.1 illustrates how the 79 statements (dots) are spatially located within the clusters. The closer the statements and clusters are together, the more they are related to one another. The stress value of the final concept map is 0.28, which matches other CM projects in which stress values range between 0.21 and 0.37 [19]. A lower stress value suggests a better overall fit of the concept map to the sorted statements.

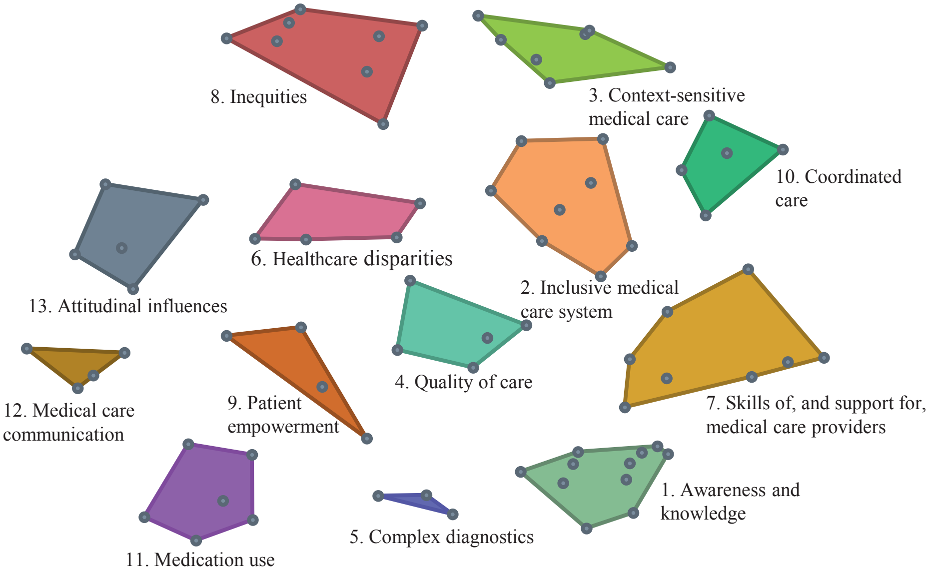

Figure 2.1 Final concept map: a spatial representation of how the statements (dots) relate to the clusters

The 13 clusters (Table 2.3) represent different aspects used to describe medical care for people with IDD. For each cluster, a description was formulated by the research team based on the statements within the clusters and informed by literature. Cluster bridging values range between 0.12 and 0.69, representing an overall moderate level of cluster anchoring. The four clusters, *Awareness and knowledge* (0.12), *Inclusive medical care system* (0.16), *Context-sensitive medical care* (0.21), and *Quality of care* (0.21) have statements with relatively low mean bridging values, indicating that these statements were frequently sorted with nearby statements. The *Attitudinal influences* cluster (0.69) has a relatively high mean bridging value.

Table 2.3 The 13 clusters and their descriptions, mean bridging values (B), and importance ratings (I)

Cluster (number of statements)	Description	B*	I†
1. Awareness and knowledge (11)	Specific awareness about, and knowledge of, the health needs and problems of people with intellectual and developmental disabilities (IDD) is essential in their medical care.	0.12	5.4
2. Inclusive medical care system (8)	The medical care system has to make reasonable adjustments to accommodate persons with IDD and their specific health needs [25].	0.16	5.4
3. Context-sensitive medical care (7)	The organization and funding of medical care for people with IDD differs between and sometimes within countries, for different age groups (children and adults), and compared with the general population.	0.21	5.3
4. Quality of care (5)	The quality of medical care for people with IDD differs between countries and preventive care is often lacking.	0.21	5.1
5. Complex diagnostics (3)	People with IDD often cannot verbalize their complaints/ symptoms and/or have unidentified conditions, making diagnosis complex.	0.26	5.5
6. Healthcare disparities (5)	The access, use, and quality of medical care differs between people with IDD and the general population [26]. For example, their needs are not adequately recognized and addressed, they experience communication difficulties, and they are subject to restrictive rules.	0.28	4.9
7. Skills of, and support for, medical care providers (8)	Medical care providers need specific skills and preconditions (e.g., time, guidelines, tools, resources to facilitate collaboration between sectors) to support the unique health and social considerations of people with IDD.	0.29	5.4
8. Inequities (8)	People with IDD do not have the same opportunities concerning medical care access, use, and quality compared with the general population. These differences, on for example the socioeconomic, geographic, and racial level, are avoidable [26].	0.30	5.5
9. Patient empowerment (4)	People with IDD are fully empowered when they have sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of their decisions concerning their medical care [27].	0.31	5.5
10. Coordinated care (5)	Medical care for people with IDD needs to be well-coordinated because many levels of care (providers) are included. This especially concerns horizontal collaboration, such as partnerships and networks within and between sectors and collaboration between health professionals [28].	0.35	5.5
11. Medication use (6)	Overmedication is common in the medical care for people with IDD, and people with IDD need to be properly informed about, and consent to, their medication.	0.40	5.1
12. Medical care communication (4)	People with IDD are often supported by others in their health communication and in making medical care decisions [8].	0.54	5.7
13. Attitudinal influences (5)	The medical care use of people with IDD is affected by attitudinal influences: assumptions that discriminate against people with IDD [29]. Because of these attitudinal influences, people with IDD are labelled, stigmatized, and not always adequately protected.	0.69	5.0

*B=bridging value between 0 and 1 (a lower bridging value indicates that the statements within this cluster were frequently sorted with statements immediately adjacent to it)

†I=importance rated on a 7-point Likert scale

Importance ratings

The importance ratings of the statements (acquired in step 5) ranged from 3.3 to 6.2 (see Supplementary Table S2.2 for the importance ratings of all statements). Table 2.3 shows that there was limited variability in ratings of importance across clusters. On average, the statements within the *Healthcare disparities* cluster (4.9) were rated least important and the statements within the *Medical care communication* cluster (5.7) were rated most important.

Sensitivity of the concept map (step 8)

Comparison of the Jackknife trials (n-1) with the original concept map shows that, on average, 16 of the 79 statements (range: 4–27) were placed in another cluster, most often a cluster nearby. The clusters representing *Inequities*, *Context-sensitive medical care*, *Medication use*, and *Awareness and knowledge* were present in all Jackknife trials. In contrast, the clusters *Attitudinal influences* and *Patient empowerment* did not appear in at least one-third of the Jackknife trials, meaning that their presence is sensitive to sampling variation. Merging these clusters with the clusters *Quality of care* and *Medical care communication* in an 11-cluster solution reduced the cluster map's sensitivity to sampling variation. However, this would have excluded the clusters *Patient empowerment* and *Medical care communication*, which provide relevant information, especially for the patient perspective. Therefore, we retained the original 13-cluster concept map.

Qualitative interpretation of the concept map (step 9)

The 13 identified clusters can be grouped in five overarching themes: (i) the active patient role, (ii) the provider role, (iii) the context of care, (iv) the consequences of care for people with IDD, and (v) quality of care (Figure 2.2).

First, the active patient role appears in cluster 9, 11, and 12. Cluster 9: *Patient empowerment* reflects a lack of preconditions to empower people with IDD to participate in medical care decisions, such as health literacy and prolonged consultations. Cluster 11: *Medication use* addresses practical problems in medical care for people with IDD, such as overmedication and lack of consent for medication. Cluster 12: *Medical care communication* indicates that there are communication challenges for people with IDD and that communication support is important.

Figure 2.2 Five themes characterizing medical care for people with intellectual and developmental disabilities

Second, the role of medical care providers is represented in clusters 1, 5, and 7. Cluster 1: *Awareness and knowledge* is the largest cluster. The statements within this cluster indicate that medical care professionals need adequate knowledge, experience, and understanding of the medical care needs of people with IDD. Cluster 5: *Complex diagnostics* addresses communicational and behavioral challenges that complicate diagnosing medical conditions in people with IDD. Cluster 7: *Skills of, and support for, medical care providers* points to the specific skills and preconditions needed by medical care providers to provide medical care for people with IDD.

Third, the influence of the context on medical care for people with IDD appears in cluster 2, 3, and 10. Cluster 2: *Inclusive medical care system* addresses lack of accessible medical care because of fragmentation and unpreparedness of care systems regarding special needs of people with IDD. Cluster 3: *Context-sensitive medical care* indicates that context influences medical care for people with IDD; the organization of this care differs for instance between countries, but also between age groups (children/adults). Cluster 10: *Coordinated care* reflects the multidisciplinary character of medical care for people with IDD and the need for coordination between medical care providers.

Fourth, the consequences of current medical care for people with IDD are presented in cluster 6, 8, and 13. Cluster 8: *Inequities* addresses the perceived unfair inequality in opportunities of people with IDD in medical care. Cluster 13:

Attitudinal influences indicates that the medical care use of people with IDD is influenced by discriminatory assumptions, such as stigmatization, labelling, and inadequate protection. Cluster 6: *Healthcare disparities* shows that there are differences in access, quality, and use of medical care for people with IDD compared with the general population.

Fifth, the quality of medical care for people with IDD is represented in cluster 4: *Quality of care*. This cluster shows that the quality of medical care for people with IDD differs between countries and preventive care is often lacking. The Quality of care cluster is situated in the middle of the concept map, indicating that it relates to all four themes around it.

Discussion

The additional analysis of the raw statements (step 3) showed that participants described medical care for people with IDD using statements that reflect current medical practice, their ideas on good practice, and aspirations for future medical care for people with IDD. Furthermore, statements could contradict each other because multiple international perspectives were included. This underlines the need for a framework to improve international understanding of medical care for people with IDD that specifically addresses IDD related themes, as this study identifies in its concept map. The developed concept map includes 13 aspects that characterize medical care for people with IDD and that can be grouped in five overarching conceptual themes: *1) active patient role, 2) role of medical care providers, 3) influence of context, 4) consequences of current arrangements, and 5) quality of care*. These themes indicate that medical care for people with IDD goes beyond the practical medical care provision between providers and patients.

Active patient involvement is an important aspect of medical care for people with IDD. Although this aspect is highlighted in existing models of medical care, communication difficulties of people with IDD and negative attitudes towards people with IDD may hinder active involvement in their medical care (decisions) [30]. People with IDD need support in communicating health problems and adequate information when making medical care decisions, and the involved medical care professionals need to adequately exchange health information and coordinate actions [31, 32]. The patient should be given the space and modes of communication to express their needs. In line with this, Mastebroek et al. (2016) identified perceived barriers and facilitators for the health information exchange between medical care providers and people with IDD [33]. Medical care providers can be well placed to facilitate the shared decision making with people with IDD [34].

Because of the complexity of diagnosing the medical problems of people with IDD, many different professionals are involved in the medical care of people with IDD. Lack of coordination between these professionals can for example lead to overmedication or unnecessary or duplicate testing [35]. Integrated care initiatives can potentially lower fragmentation in the medical care for people with IDD, but this has not been demonstrated empirically due to lack of clear definitions and the difficulty of applying disease-specific initiatives to IDD [35]. Many people with IDD have underlying conditions that are not identified due to behavioural or communication challenges and challenges in presentation [30]. Despite the increasing knowledge on the needs for specific skills and knowledge in medical care providers [11, 36], authors of recent review articles agree that medical care for people with IDD still lacks adequate support [9–11, 37, 38]. This lack can possibly be addressed by systematically increasing the attention/priority for the special medical care needs of people with IDD in medical curricula and education [39, 40].

While similar preconditions are recognized internationally, the context and organization of medical care differs between and sometimes within countries and for different life stages [9, 14, 15]. The international differences are also underlined in this study by the contradicting statements. The different international responses to the still ongoing COVID-19 pandemic have shown that understanding the context in which medical care for people with IDD is provided is important to learn from other countries and improve the medical care for people with IDD [41]. There is a need for a better understanding of the different international models of medical care for people with IDD [10]. This study's concept map provides an exploration of themes and aspects that are relevant in medical care for people with IDD complementary to the already existing models of medical care, which can be used as a basis for future studies that can further elaborate on these themes and aspects.

Limitations

This study's findings should be interpreted in light of the following limitations. This study included 25 participants. This number is in line with the recommendations for CM studies [20–22]. Given the exploratory and international nature of this study, sampling focused on heterogeneity of participants and snowballing allowed us to recruit a wide diversity of participants, originating from 17 countries and six continents. The participants provided us with the opportunity to set up a first exploration of which aspects constitute the concept of medical care for people with IDD. Nevertheless, future studies with larger respondent groups will be needed to further elaborate on these aspects.

This study reflects only expert researchers' and practitioners' perspectives on medical care for people with IDD and lacks perspectives of people with IDD themselves and their caregivers. Explicating concepts is helpful for people with IDD to share their perspectives on complex topics [42], and the themes and clusters identified in this study can provide a basis for people with IDD to be actively involved in future studies.

Although the CM approach has been widely applied in health care research and is suitable to disentangle complex phenomena into more simple individual components [43], it requires further critical assessment. For example, the quality of results is often assessed based on the stress values of previous empirical studies [44]. However, no clear standards for acceptable stress values have been established analytically. Péladeau and Dagenais [44] contend that reversing the order of multidimensional scaling followed by hierarchical cluster analysis has major advantages over the original order. Because the software used was limited to the original order of analysis, this study assessed additional sensitivity to sampling variation through a Jackknife procedure, which has been applied in a similar study before [45]. Moreover, we opted to add additional qualitative analyses of the raw statements and of the final cluster map to better understand and represent the collected data and prevent loss of information. The additional dimension in answer types (current medical practice, ideas on good practice, and aspirations for future medical care for people with IDD) is information that would have been lost in the traditional concept mapping procedure.

The CM software allowed for international participants to contribute to this study online. However, language might have been a barrier for non-native English speakers. Also, nuances in meaning may have been lost in translation between formulating statements and interpretation by other participants and the research team. However, the CM method was suitable to provide a first exploration of the concept of medical care for people with IDD.

This study aimed to explore themes and aspects of medical care for people with IDD. The collected statements show that participants did not always make a clear distinction between medical care and health care. This highlights the interrelatedness of both concepts, also within IDD specific care. During the CM procedure, the research team made decisions on how to proceed. These decisions included evaluating the sorting and rating data and choosing the number of clusters in the final cluster map. For transparency, these processes were described in the methods section; detailed information is available upon request. We recommend future studies to also include this transparency and an additional qualitative analysis of the collected responses to better understand and represent the collected data and prevent loss of information.

Conclusions

By providing an explorative overview, this study can serve as a first step towards an improved understanding of the concept 'medical care for people with IDD'. This study shows that the medical care for people with IDD is described as encompassing more than only the practical medical care provision between providers and patients. Themes such as active patient involvement, coordination of care, contextual influences on the medical care, and consequences of the medical care are also important themes to consider. The themes, clusters and statements identified through this study move beyond objective and countable data and help to provide additional content and context for the specific patient group of people with IDD to the dimensions of previous models of medical care. Future studies can further elaborate on these themes.

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Appendix

Supplementary Table S2.1 The 92 unedited responses to the focus prompt

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say…
1	Private public participation
2	Overmedication is a problem for many with an IDD. This may be a problem in families too, but especially present in long term care facilities (most residents are on medication prescribed by psychiatrists). Lack of consent is a problem + side effects!
3	Poverty is a huge problem and medical care and health is closely related to poverty. Most people with IDD are likely to live in households with low income.
4	Prevention is lacking for people with IDD. Medical staff &parents report that many people with an IDD go to their GP/hospitals too late. This is probably due to stigma & previous bad experience + lack of services (e.g., too far from where they live).
5	There is a scarcity of practices that accommodate the special communication needs of people with IDD. Augmentative or alternative communication (AAC) options are not available at health services. Medical staff wouldn't even know how to use AAC.
6	Medical care for people with an IDD in Hungary is largely underfunded. There is no training for medical professionals about the special needs of people with IDD. Thus, quality of service at hospitals or GPs is usually low for people with IDD.
7	In JAPAN, Decision Support for the people who have IDD, especially in medical field, is a problem nowadays. Who has a right to decide to take medicine, to accept surgery, on behalf of them? Family members, care takers bear the responsibilities.
8	In Japan I can find more specialists has come to understand people with IDD nowadays. Every doctor has different values and I think it is important to communicate thoroughly with specialists by the primary care doctors for people with IDD.
9	It is completely under funded
10	In Canada, adults with IDD access general, publicly funded health care. There remain many people in the healthcare workforce that do not feel that they have the competencies to support the unique health and social considerations of this group.
11	There are guidelines and tools to support health care providers for this group
12	In Canada, medical care for adults with IDD is not well coordinated between primary and specialist care and many individuals do not have access to comprehensive team-based primary care.
13	In Canada, there remain many adults with IDD that do not receive recommended preventative care and have underlying conditions that are not identified secondary to behavioral/communication challenges and challenges in presentation.
14	Do any of us have a nurse following us around to pass medications when we are out of our home? Why is this normal for DD population?

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say…
15	Med Rule that allows DSPs pass medications is too restrictive and doesn't allow for residents to travel much less attend special olympics without a nurse to travel with them to pass meds to them. What facility has this kind of money?
16	our folks are being pushed into MMAI programs which require referrals for specialists, many not in the immediate area. Strains resources to get them to appointments and delays care. They lose their current PCP and forced to see another.
17	medical care is strained by providers who do not understand that our folks don't understand their questions and./or are poor reporters…they must use staff to fill in the gaps of information but often ignore staff, prompting unnecessary testing.
18	During Covid we find that we are essential workers. We are not paid that way, how can we provide high quality care when we cannot attract high quality workers with the salary the state funds? Our population suffers the most.
19	DD diagnosis does not allow for them to enter nursing home to live out their lives…they can NEVER retire also must do programming no matter their age or progressing medical conditions. This is NOT normalization. Once 65+ why choices gone?
20	Approaches that aim to increase self-determination of the person with ID, such as shared decision making and supported decision making are promising practices, but they are only being used by few people in small pilot areas.
21	Families and people with ID have significant challenges with transition from pediatric medical care providers. There are few capable medical care providers for adults in many areas.
22	In the US, there is not agreement about the best approach - whether it is to establish specialized care centers or whether it is better to support all clinicians to provide good integrated care.
23	People with ID in the US generally do not have access to specialized clinicians who have particular knowledge and training.
24	There are geographic, socioeconomic, and racial inequities in access to medical care for the population as a whole.
25	In Japan, medical care is defined as a part of medical treatment which is provided by non-medical staff or family members of people with IDD at their homes or schools, other than in medical hospitals.
26	There is specialized education for people with IDD, but not medical specialty in IDD in Japan. However, we do have a category called Ryoiku in which people with PIMD are cared for their medical, healthcare and welfare issues.
27	The specialist skills to assess and provide treatment for people with IDD is not acknowledged as a specialty, like cardiology or neurology. It is a specialist skill to understand the comprehensive health needs of people with IDD.
28	There is no financial incentive for adequate healthcare to be provided by medical staff, it is usually only those with an interest in the area work in this space.

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say…
29	People with IDD have multiple barriers to accessing the healthcare they need. Medical staff often lack the expert knowledge to assess and manage health needs, communication is insufficient, not enough education available, rights of IDD not acknowledged
30	Several reports in Norway on Health status and health monitoring of adult people with ID, have for many years told us that it is not sufficient. Care workers do not capture signals of diseases soon enough to be able to treat.
31	In Norway, we lack both general- and acute health knowledge among care workers who work with people with ID.
32	Ageing and Health has developed a hospital passport for people with ID to bring when treated in hospitals or other units.
33	All habitants in Norway have a general practitioner, and people with ID are entitled a yearly health check by their GP. But not all of them receive a Health check due to lack of resources.
34	In Norway we have habilitation services that offer multidisciplinary inpatient and outpatient services for people with ID. Children and adult care are separated.
35	In Switzerland, special needs of PWID, especially adults, and their care have to be recognized and adequately been reimbursed.
36	There are few specialized units in Switzerland available for people with ID. Global standards of medical care is high, therefore most of PWID get adequate treatment. However: care in the community and for challenging behavior must be improved.
37	A particular issue arises at transition from pediatric to adult care- as children with IDD are surviving longer there is an issue with who provides ongoing care for them - adult practitioners are not used to looking after them in the same way
8	There is an awareness of the increasing need to support people with IDD in Australia. However, there are still many misconceptions about their needs and the complexity of their conditions.
39	In Israel I believe that the medical and developmental services are all in all very good for kids. However, I think that there is a gap between their services and the ones that are offered to adults.
40	Average life span in most west African countries range from 35-50 so when you have an IDD life span is even shorter due to a lot of factors because the quality of life and healthcare is completely below standard for people with IDD.
41	The most vulnerable are not always the most protected so it makes a really difficult situation even worse when you are located in the rural setting because there is inadequate healthcare and inequalities of care
42	Children suffer a lit especially once with IDD, YHEY do not fit the box and are labelled in the society
43	The rural area is the most deprived due to lack of accessibility to healthcare and poor road networks
44	It needs structure and dedication
45	The disability bill has just been signed into law and this took so long but up to now it is not being enforced

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say…
46	People with IDD their needs are never met and no formal provision to meet their needs i.e. some hospitals don't even have ramps etc., people are not being treated with dignity or informed properly regarding their diagnosis
47	Medical care for people with IDD is very appalling in my country and there are 2 types of medical care: the Public owned by the government and the private owned by individuals or group of individuals. The government healthcare is divided into 3 tiers
48	Medical care for people with IDD is very appalling in my country and there are 2 types of medical care: the Public owned by the government and the private owned by individuals or group of individuals. The government healthcare is divided into 3 tiers
49	Most ID persons can only get medical care if their support workers or carers decide they need it and seek it out for them. There are no clear / simple ways for person with ID to reach out to GP if they feel they need it.
50	If the ID person cannot verbally communicate and articulate what is wrong, then treatment is delivered 'around' them - directed at whoever is supporting them rather than the person themselves
51	Most medical providers don't seem to understand the impacts of complex disabilities or how to support the conversations which need to take place for their appropriate care
52	It is not readily accessible and where it is accessible, there is stigma attached to it so few people will willingly seek treatment from the facilities providing medical care for people with IDD
53	Psychotropic drugs are used too often in the medical care of people with IDD in my country.
54	It would be good to reduce the medicalization of medical care for people with IDD in my country
55	Medical care for people with IDD is not given enough prominence in my country.
56	Improving communication between medical practitioners, allied health, and support organizations would improve medical care for people with IDD in my country.
57	Medical care for people with IDD in my country is fragmented.
58	Some children with IDD do not have access to medical care as it is not considered as priority since it is not life threatening.
59	Most children with ID are first suspected by their parents and neighbors/ community members especially in rural area. In urban, they are first suspected by class teacher in nursery or school especially for those children with ID with working parents.
60	There is a use of both indigenous and western knowledge in the diagnosis of ID. Conditions of children are often suspected by parents especially those in rural areas using indigenous knowledge
61	Most children with ID who don't present any other clinical condition, are first suspected by their parents, mainly when they have older siblings, or by teachers on daycare and school. Physicians seem more alert to severe than mild conditions.

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say...
62	Children with genetic conditions coursing with ID tend to get earlier diagnose and treatment. Those who fall out of this, e.g., ASD, mild CP and others, are less likely to get involved in early intervention programs timely.
63	Overall, it varies greatly from one region to another, but most states and cities rely on an unprepared health care system when it comes to diagnose, and the education system mix inclusive and segregate options.
64	regarding ID health care there is need for a huge effort of all stakeholders to come to knowledge transfer, collaboration, and integrated care between the different health care sections
65	we are lucky to have a specialized training on ID medicine. We are not lucky that there are barriers between the ID specialized care and primary care and between ID specialized care and mental health care.
66	4) Establish in which countries there are specifically courses dedicated to IDD in the health careers at university. If there are plans in this knowledge for pre-graduate students, and the number hours which is dedicated to IDD by students. Much of this
67	3) Establish the percentage of schools dedicated to IDD, in relation to normal schools, in the different countries.
68	of their funds and how they are used in general. This would allow establishing regional comparative indices of concern for IDD over time.
69	the responsible administrator for these programs if they exist. 2) Establish an International voluntary list of Governmental and Non-Governmental Organizations that are dedicated to supporting IDD in the different countries, indicating the source
70	1) Establish a comparative document that lists the laws with which the different States have assumed the reality of people with IDD. With a table that includes the percentage of GDP dedicated to support disability, its national geographic distribution
71	Most providers do not understand the complexity of their care. They are used to speaking directly with the patient and many of our residents have IQ of small children or cannot verbalize or answer questions accurately.
72	People with IDD within disability support in the municipality do have some medical support specialized in IDD (nurses, occupational and physiotherapists), however without primary health care competence - possible leading to unequal care in a way
73	Primary health care available for all citizens, exist on 300 places in a 2 million city such as Stockholm, with a lot of doctors on each place in turn meeting to few individuals with IDD to get experience enough to see pattern connected to the IDD
74	Although information about all different familiar syndromes is available on governmental webpages health care professionals seldom have the time (or knowledge about the need) to look into and learn about different syndromes comorbidity
75	The education system for doctors as well as nurses have very little education in this populations needs
76	In Sweden similar to Canada children and adolescents with IDD are mostly well served from the health care organizations. It is after that, when they have to find help in the general health care system that it gets problematic.

Raw statements	Focus prompt: If you ask me to describe medical care for people with intellectual and developmental disabilities (IDD) in my country, I would say...
77	Knowledge is very scarce within the health care system among what might follow an IDD concerning difficulties such as understanding verbal information or the need for extra time to be able to communicate needs and questions.
78	just as unsure with regards to health insurance as it is for the general population, but with higher health care use/needs
79	not enough time (more time needed than usual) to involve the person with ID in decision-making
80	lack of specific knowledge on ID in health care professionals
81	depending on available expertise in geographical area
82	not accessible enough
83	in silos
84	it is very much multidisciplinary
85	it is still influenced by stigma
86	it does not matter if you live in a high-income country or a lower income country, people with ID always depend in some way on the people around them, their care system, to signal needs and to have access to healthcare.
87	lack of awareness and knowledge on the health needs of people with ID and how you can signal and assess those needs.
88	it needs to be more proactive in order to reduce health inequity and underdiagnoses and with that improve quality of life. The ID physician is trained to do so.
89	very heterogenous and different per country and even within one country you find different standards, approaches etc.
90	When someone with ID is in hospital, if they have family caregivers, they can have someone to advocate for them, but if their family has passed or is not involved, they may struggle having advocates in hospital.
91	In Canada, children and teenagers have good supports as long as they still go to school, but once they finish secondary school it can be hard to access care.
92	In Canada, it varies a lot by different provinces. Some provinces have very good medical care for people with ID, others not so much.

Supplementary Table S2.2 Overview of statements per cluster with associated bridging values (B) and mean importance (I)

ID	Statement	B*	I†
	Cluster 1: Awareness and knowledge	0.12	5.4
5	There is an awareness of the increasing need to support people with ID	0.324	5.4
7	Most medical care providers do not understand the impacts of complex disabilities	0.034	5.7
8	Medical care providers are not aware of the need to learn about different syndromes	0.005	5.5
11	There is a lack of both general and acute health knowledge and skills among care workers who work with people with ID	0.082	6.0
13	The education system for health care professionals and medical professionals has very little education in the needs of people with ID	0.071	6.1
14	There is a lack of knowledge on the health needs of people with ID and how to signal, assess, and manage those needs	0.055	5.9
16	Medical care providers meet too few individuals with ID to get enough experience to see patterns connected with ID	0.000	5.4
19	Most medical care providers do not seem to understand how to support the conversations which need to take place for appropriate care	0.106	5.6
36	Medical care providers must use staff to fill in the gaps of information but often ignore staff	0.134	4.9
62	More specialists have come to understand people with ID nowadays	0.113	5.4
75	There is use of both indigenous and western knowledge in the diagnosis of ID	0.431	3.3
	Cluster 2: Inclusive medical care system	0.16	5.4
10	People with ID generally do not have access to specialized clinicians who have particular knowledge and training	0.199	5.9
35	Many people with ID do not have access to comprehensive team-based primary care	0.108	5.5
37	Medical care for people with ID is fragmented	0.162	5.6
38	Most states and cities rely on an unprepared health care system when it comes to diagnose	0.203	5.3
43	Medical care for people with ID is not given enough prominence	0.106	5.8
64	The organization of the medical care system delays care	0.156	5.6
74	Medical treatment is only provided by non-medical staff or family members of people with ID	0.190	4.4
	Cluster 3: Context-sensitive medical care	0.21	5.3
2	Medical care for people with ID varies greatly between countries and from one region to another	0.253	5.8
32	There is a gap between the services offered to kids and adults: they are very good for kids	0.260	5.8
40	Medical care for people with ID is underfunded	0.158	5.6
41	There is no financial incentive for adequate healthcare provision for people with ID by medical staff	0.192	5.4
48	Medical care for people with ID is just as unsure with regards to health insurance as it is for the general population, but with higher health care use/needs	0.229	4.7
55	Adults with ID access general, publicly funded medical care	0.199	5.5
56	There are two types of medical care: the public, owned by the government, and the private, owned by individuals or groups of individuals	0.155	4.1

ID	Statement	B*	I†
	Cluster 4: Quality of care	0.12	5.1
44	Prevention and proactive care are lacking in medical care for people with ID	0.100	5.9
49	Quality of services for people with ID in hospitals or at GP's is usually low	0.096	5.2
50	Global standards for medical care are high. Therefore most of the people with ID get adequate treatment	0.099	4.3
51	Medical care for people with ID is completely below standards	0.180	4.7
65	Medical staff and parents report that many people with ID go to their GP/hospital too late	0.148	5.2
	Cluster 5: Complex diagnostics	0.26	5.4
20	Medical care providers are used to speaking directly with the patient, but many people with ID have a low IQ and cannot verbalize or answer questions accurately, which is problematic	0.301	5.7
58	Many people with ID have underlying conditions that are not identified secondary to behavioural/communication challenges and challenges in presentation (diagnostic overshadowing)	0.215	5.6
59	There is too much underdiagnosis	0.260	5.0
	Cluster 6: Healthcare disparities	0.28	4.9
24	There are no clear/simple ways for a person with ID to reach out to a GP if they feel they need it	0.195	5.4
42	People with ID, their needs, and their care need to be recognized and adequately be reimbursed	0.344	5.8
66	Children with genetic conditions coursing with ID tend to get earlier diagnose and treatment. Those who fall out of this are less likely to get involved in early intervention programs timely	0.191	5.4
76	Rules that allow direct support persons to pass medications to people with ID are too restrictive	0.320	3.4
78	Intellectual disability diagnose overrules retirement and nursing home care on old age	0.374	4.5
	Cluster 7: Skills of, and support for, medical care providers	0.29	5.4
9	There are few competent medical care providers to support the unique health and social considerations of people with ID	0.326	5.9
12	Health care professionals seldom have the time to look into and learn about different syndromes	0.040	5.6
33	Medical care for people with ID is very much multidisciplinary	0.464	5.3
39	There is a need for a huge effort of all stakeholders to come to knowledge transfer, collaboration and integrated care between the different healthcare sections	0.611	5.8
52	The specialist skill to assess and provide treatment for people with ID is not acknowledged as a specialty, like cardiology or neurology	0.147	5.2
54	In some countries, there is a specialized training on ID medicine, however, these specialists do not have primary health care competencies	0.211	4.6
63	There are guidelines and tools to support health care providers for people with ID	0.312	5.5
73	The values of the medical care provider influence the provided care	0.239	5.5

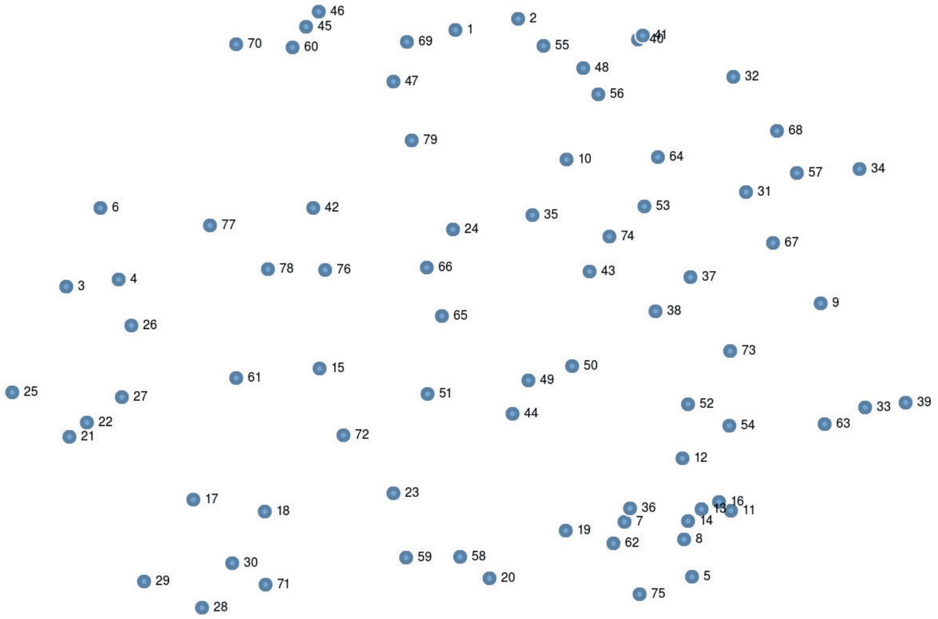
ID	Statement	B*	I†
	Cluster 8: Inequities	0.3	5.5
1	There are geographical inequities in access to medical care for people with ID	0.134	6.0
45	There are socioeconomic inequities in access to medical care for people with ID	0.219	5.9
46	There are racial inequities in access to medical care for people with ID	0.294	5.5
47	There is a lack of accessibility of medical care for people with ID in rural areas due to, among other things, poor road networks	0.221	5.3
60	Medical care for people with ID is closely related to poverty	0.387	4.9
69	There are inequalities of medical care for people with ID	0.208	6.0
70	In rural areas, people with ID are first suspected by their parents and neighbors/community members. In urban settings, they are first suspected by their parents or teachers on daycare and school	0.691	4.7
79	An overview of relevant laws, organizations, schools dedicated to ID students, and funds is lacking	0.243	5.3
	Cluster 9: Patient empowerment	0.31	5.5
15	There is not enough education available for people with ID	0.314	5.6
23	People with ID are not treated with dignity in medical care provision	0.267	5.2
61	More time is needed to involve a person with ID in medical decision making	0.410	6.1
72	Some people with ID do not use medical services because of previous bad experiences	0.243	5.1
	Cluster 10: Coordinated care	0.35	5.5
31	Children and adult medical care are separated and transitions are problematic	0.210	5.8
34	Medical care for adults with ID is not well coordinated between primary and specialist care and mental health care	0.504	5.7
57	Medical care for people with ID is very heterogenous	0.428	5.8
67	There is no agreement about the best approach - whether it is to establish specialized care centers or to support all clinicians to provide good integrated care	0.291	5.2
68	Medical care for people with ID can be provided in the community (at the homes of people with ID, at their schools) or in medical hospitals	0.304	5.2
	Cluster 11: Medication use	0.4	5.1
17	Lack of consent for medication is a problem in medical care for people with ID	0.462	5.0
18	People with ID are not informed properly regarding their diagnosis	0.346	5.5
28	Overmedication is a problem for many people with ID because of the side effects	0.393	5.5
29	Overmedication for people with ID is especially present in long term care facilities	0.408	4.9
30	Psychotropic drugs are used too often in the medical care for people with ID	0.306	4.9
71	It would be good to reduce medicalization of medical care for people with ID	0.479	4.8

ID	Statement	B*	I†
	Cluster 12: Medical care communication	0.54	5.6
21	Decision support for people with ID, especially in the medical field, is a problem nowadays	0.565	5.4
22	Approaches that aim to increase self-determination of the person with ID, such as shared decision making and supported decision making are promising practices, but they are only being used by few people in small pilot areas	0.544	5.2
25	Treatment is often communicated with whoever is supporting the person with ID rather than the person him/herself	0.577	5.7
27	People with ID need to have someone to advocate for them in the hospital	0.471	6.2
	Cluster 13: Attitudinal influences	0.69	5.0
3	There is stigma attached to seeking care from the facilities providing medical care for people with ID	1.000	4.5
4	People with ID are labelled in society which affects their medical care use	0.667	4.9
6	People with ID are not always protected	0.801	5.5
26	People with ID are always dependent in some way on the people around them and their care system to signal needs and to have access to health care	0.530	5.9
77	Restrictive medication rules can hinder people with ID in travel & activities	0.447	4.1

*B=bridging value between 0 and 1

†I=importance rated on a 7-point Likert scale

Supplementary Figure S2.1 Point map visualizing the relationship and proximity of statements to one another



Chapter 3

International perspectives on healthcare for people with intellectual disabilities

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

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 [1]. Even though 187 countries or states have ratified this Convention [1], 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 [3, 4]. 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 [4, 5] and differences in access to healthcare during the COVID-19 pandemic [6, 7].

The organization of healthcare for people with IDD differs internationally and each country has developed unique practices to give shape to this healthcare [8, 9]. 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 [10]. 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 [11]. 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 [13, 14]. 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 in 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.

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 analysed using thematic content analysis [14]. 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 3.1. To obtain more insight in the themes, sub-themes were identified for the qualitative information provided in the papers (Table 3.2).

Table 3.1 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

Table 3.2 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 Data 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

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, and 4) Challenges, and 5) Best practices.

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 disability who have additional developmental disabilities, while in other cases the term is understood to collectively refer to individuals with intellectual disability and individuals with other developmental disabilities who do not have intellectual disability, 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 0.4-2.3% (Table 3.3). These numbers are based on estimations, registrations of public health and care services, national census or survey studies, or governmental sources resulting in 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 lead to differences in who is counted, resulting in a wide range of prevalence numbers within and across countries. In addition, there is unclarity about the terms ID (intellectual disability) and IDD (intellectual and developmental disability). 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 in 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 level. 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.

Table 3.3 General characteristics: prevalence of people with IDD

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

* concerns ID (not IDD)

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 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 towards greater inclusion and quality of healthcare.

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, behavioural 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.

4. Challenges in healthcare for people with IDD

Challenges raised in the special issue papers were grouped into four subthemes as described in table 3.4.

Table 3.4 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.

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.

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 was 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.

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 common 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.

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. Firstly, 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. Secondly, 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.

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.

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, authors 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.

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.

Firstly, the synthesis demonstrates four types of barriers to accessible healthcare for people with IDD that are pressing across countries. These barriers have also been identified in literature. A literature review [15] emphasized attitudinal and organizational barriers to healthcare access for people with IDD. A recent review [16] 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 [17]. This synthesis supports the need for more accessible healthcare for people with IDD as a universal goal.

Secondly, 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 [18-20]. Furthermore, the need to better prepare medical students in providing healthcare for people with IDD has been acknowledged [17, 21, 22]. 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.

Thirdly, 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 [23, 24]. 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 [25, 26] 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 towards improving their healthcare.

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. Firstly, 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.

Secondly, 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 perspective and approach may differ from that 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.

Thirdly, 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.

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 [27]. 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.

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.

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Chapter 4

Specialized medical care for people with intellectual disabilities: a retrospective cohort study in an outpatient ID practice

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Abstract

Background People with intellectual disabilities (ID) experience complex medical care needs and high levels of multi-morbidity. In mainstream healthcare, these needs might remain undetected leading to unmanaged health problems and avoidable deaths. In the Netherlands, GPs can refer to specialized ID physicians when ID-specific expertise is required. Little is known about the characteristics of specialized medical care for people with ID. This study explores the characteristics of specialized medical care for people with ID, including the interplay between medical, psychological, and context-related problems.

Methods A retrospective cohort study using medical records of patients with ID who had visited the outpatient ID practice in Nijmegen, the Netherlands. Medical records (n=128) were analyzed using descriptive statistics, focusing on 1) reasons for initial consultation, 2) health-related problems identified during initial consultation, and 3) disciplines involved following initial consultation. Analyses were performed separately for patients who were referred by a medical professional and patients who visited the practice for proactive health checks related to the etiological diagnosis.

Results Patients often initially visit the outpatient ID practice for one type of complaint, most often psychological. Diverse, multiple, and interconnected problems were identified during specialized medical ID consultation. A range of specialist professionals (n=25) were involved by the ID physician.

Conclusions The health-related problems of people with ID seen at the outpatient ID practice are diverse and interconnected, and originate from an interplay between medical, psychological, and context-related problems. This complexity is not mirrored in the reasons for referring to the outpatient ID practice. It is essential to go beyond medical views and assess health complaints in an integrated way, including the way ID can influence all levels (physical, mental, contextual) of the experienced health issue within the context of everyday life.

Background

People with intellectual disabilities (ID) have more complex and different medical care needs than the general population [1, 2]. About 120 million people, or 1.5% of the world's population, have ID [3-6]. An ID is defined as significant limitations that originate during the developmental period in both intellectual functioning and adaptive behaviour [7]. People with ID have different morbidity patterns and experience more comorbidity and syndrome-related health problems compared with the general population [8, 9]. The complex health problems of people with ID often reach beyond medical problems alone and are influenced by psychological and context-related problems [2, 10, 11]. The influence of these problems and their interactions can be easily overlooked in people with ID, because of difficulties such as atypical symptom presentations and difficulties in communication and health information exchange between patients, professionals, and informal carers [12, 13].

Not all medical care providers are familiar with the special medical care needs of people with ID. For example, GPs view their current medical care provision for people with ID to be of limited quality and effectiveness and both GPs and medical specialists report a lack of initial training in providing medical care for people with ID [9, 14-16]. Specialized ID training and education for medical care providers has been widely suggested as a solution to improve healthcare for people with ID [2, 17-20]. However, there is need for rigorous studies on the role of specialist ID services in facilitating access to healthcare services or on how they may support mainstream healthcare providers in providing medical care for people with ID [21].

The Netherlands has a specialization for medical care for people with ID. Physicians who complete a three-year vocational post-graduate training in population-specific knowledge, skills, and attitude are registered as specialized ID physicians. The ID physician is a population-oriented general specialist with expertise in health problems related to or coloured by ID, in people of all ages and ID levels [22]. ID physicians predominantly work in care organizations, but there are also outpatient clinics where ID physicians work and to which the GP or medical specialist can refer patients with ID when ID-specific expertise is required [22].

The setting of this outpatient clinic offers the opportunity to explore the value of specialized medical ID expertise in facilitating the identification of health-related problems in people with ID and the characteristics of specialized medical care provided to people with ID in practice. To illustrate this, we provide an example case; A GP refers a patient with behavioural problems (psychological problem) to the outpatient ID practice. During the consultation, the ID physician discovers that the patient experiences hearing difficulties. The ID physician does a medical exam and finds out that the patient's ears are clogged from wax build-up (medical problem). Not hearing, understanding, and comprehending his environment and vice versa (context-related factor) resulted in an angry and agitated patient. When the ears were cleared from earwax, the patient's behaviour stabilized to the point where it was not problematic. An audiologist was engaged by the ID physician to check whether the patient needed hearing aids.

This study focuses on 1) the reasons for initially visiting the outpatient ID practice, 2) the health-related problems identified during initial consultation, and 3) the disciplines involved following this consultation.

Methods

Setting and design

This is a retrospective cohort study using routine data from the outpatient ID practice in Nijmegen, the Netherlands. Since 2015, the outpatient ID practice registers the provided specialized medical care for people with ID in electronic patient health records. All patient encounters have been registered electronically using a health information system (TransHIS). This system registers the reason for consultation and the main health problem(s) during consultation according to the International Classification of Primary Care, Second Edition (ICPC-2) [23]. Furthermore, ID physicians added clinical entries in an electronic journal.

The outpatient ID practice collects informed consent (opt-in) for the use of patient data for research purposes since 2020. For patients who visited the practice before 2020, informed consent was obtained via an opt-in procedure. Informed consent forms were composed in conformity with the GDPR (General Data Protection Regulation) in easy-to-read language (see Supplementary Files S4.1 and S4.2). If the patients did not have the capacity to consent (e.g., children or people with moderate to profound ID), their legal representative signed.

This study extracted data from the health records of patients who visited the practice between April 2015 and March 2021 when informed consent was present (preregistration https://doi.org/10.17605/OSF.IO/W8GA5). The Medical Ethical Committee (CMO regio Arnhem – Nijmegen) waived the need for further ethical assessment [2020-6090].

Study population

The patient population of the outpatient ID practice has a varying level of ID from mild to profound. Two groups of patients receive care from the outpatient ID practice in Nijmegen. The first group (consultation visit (CV) group) comprises patients referred to the outpatient ID practice by a medical professional, often a GP. These patients have a health complaint or problem requiring ID specific expertise, thus having a specific, active care demand. The second group (health check (HC) group) comprises patients who have an etiological diagnosis of their ID (e.g., 22q11 syndrome) and visit the outpatient ID practice for proactive health checks related to the etiological diagnosis. These patients are generally referred by a developmental paediatrician and younger in age. Because of the different reasons for visiting the outpatient ID practice, the results for the two groups will be described separately.

Data

Data from initial consultations were extracted from the electronic medical records by the Radboudumc Technology Center (RTC) Health Data of the Department of Primary and Community Care. Data were pseudonymized and provided to the research team. These records include information on the reason for consultation, anamnesis, physical examination, evaluation and conclusion, and additional actions, registered in ICPC-2 codes and written text clinical entries in the electronic journal. Extracted data consisted of patient demographics, reasons for initial consultation (entered at registration), health-related problems identified during initial consultation, and disciplines involved following initial consultation. The reasons for initial consultation were extracted by combining two types of data: 1) registered ICPC-2 codes on the reasons for initial consultation and 2) clinical entries in the electronic journal (Supplementary Table S4.1). The clinical entries consisted of open text and were manually coded by the first author using ICPC-2 codes to facilitate merging the two types of data. After merging, the complete list of reasons for initial consultation was grouped into three types: medical, psychological, and context-related (Supplementary Table S4.2). Medical problems concerned for example problems related to the digestive or cardiovascular system, psychological problems could be behavioural or sleep problems, and context-related problems concerned for example problems with work, housing, or social contacts.

The health-related problems identified during initial consultation were extracted by combining information from both the ICPC-2 codes assigned by the ID physician during initial consultation and the clinical entries. The health-related problems mentioned in clinical entries were coded, following a self-developed consensus coding scheme grouping medical, psychological, and context-related problems using Atlas t.i. software, by three researchers (two ID physicians and the first author) (inter-coder agreement = 72%). Cases of doubt were discussed with all coders until consensus was reached. The ICPC-2 codes registered by the ID physicians on health-related problems identified during initial consultation were also grouped following the three types and combined with the health-related problems identified in the clinical entries. This resulted in a complete list of health-related problems identified during initial consultation. Additionally, an automated search was performed in Atlas t.i. to identify disciplines involved after initial consultation on advice of the ID physician.

Analyses

Analyses were performed separately for the two groups of patients. First, the (number of) different types of reasons for initial consultation were explored using descriptive statistics. Thereafter, we described the reasons that were most prevalent within the three types (medical, psychological, and context-related). Second, descriptive analyses were performed to explore the (number of) different types of health-related problems identified during initial consultation. To explore a possible pattern between the reasons for initial consultation and the health-related problems identified during initial consultation, a cross tab analysis was performed for the CV group. Third, to identify the professionals who were involved for referral, assistance, examinations, or treatment after initial consultation, descriptive analyses were performed. IBM SPSS Statistics version 25.0 was used for all statistical analyses.

Results

Demographics

At extraction date, records from 526 patients were available for analysis and were asked for informed consent. 128 patients provided consent and data from their health records were used for this study, with non-response to the informed consent being the main reason for exclusion (Figure 4.1). The sex and age distribution in this study's population is representative of the total patient population at the outpatient ID practice.

Of the 128 included patients, 91 (71.1%) belonged to the consultation visit group (CV group) and 37 (28.9%) to the health check group (HC group) (Figure 4.1). Table 4.1 presents descriptive statistics of the study population for the two groups separately. The median age of patients in the CV group was higher than that of patients in the HC group: 25 (IQR: 18–40) versus 17 years (IQR: 7.5–21) years, respectively. In the CV group, 80% were younger than 50 years, with the majority between 18 and 34 years (46.2%). In the HC group, all patients were younger than 50 years at initial consultation, with the majority being younger than 18 (54.1%). Of the patients in the CV group, 34.1% had a known etiological diagnosis, whereas in the HC group the corresponding figure was 89.2%.

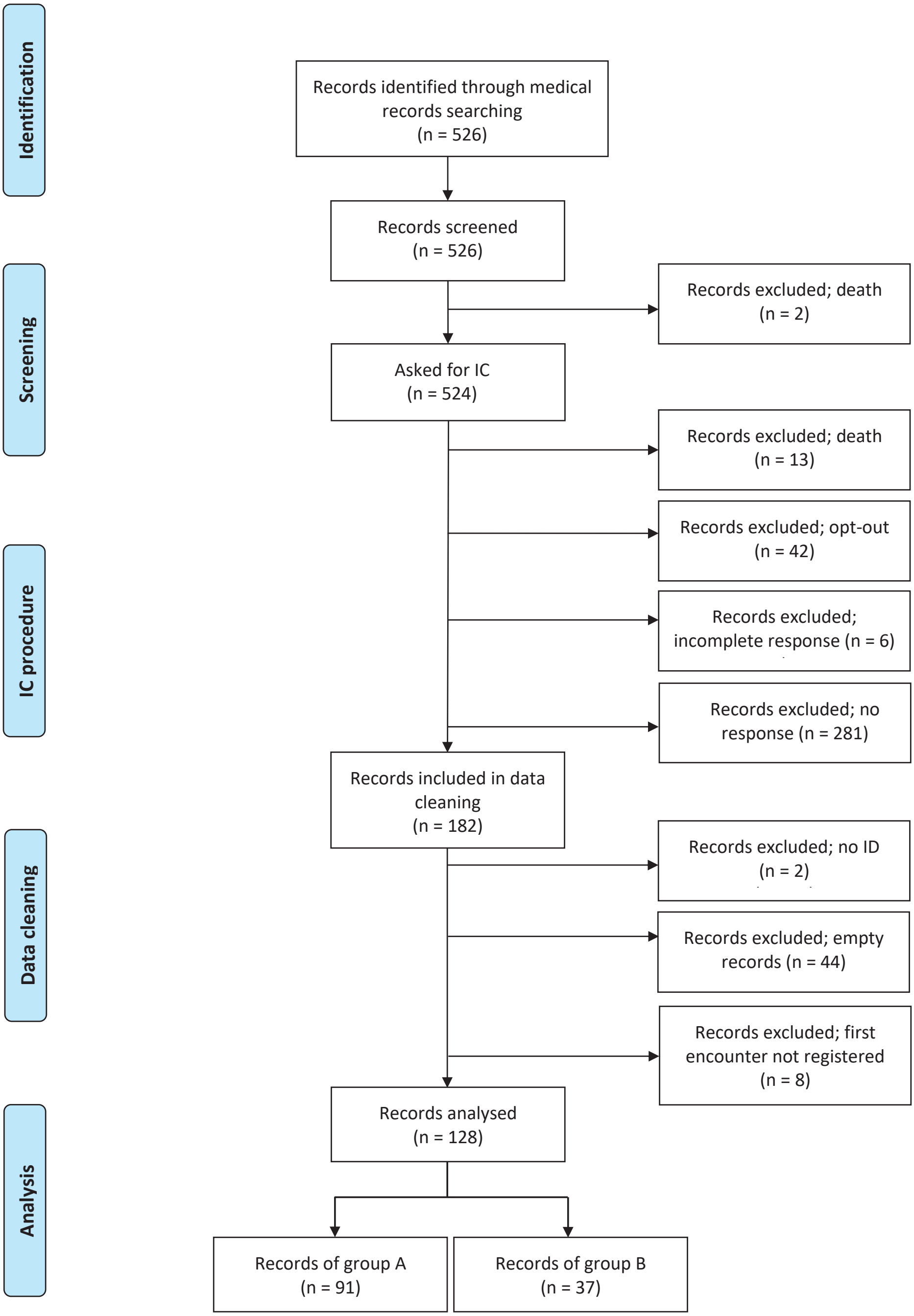

Figure 4.1 Flow chart of participants

Table 4.1 Descriptive statistics presented separately for the consultation visit group (CV group) and the health check group (HC group)

	CV group N = 91	HC group N = 37
Sex, N (%)		
Males	48 (52.7)	17 (45.9)
Females	43 (47.3)	20 (54.1)
Age at initial consultation		
Median (interquartile range)	25 (18–40)	17 (7.5–21)
Age groups at initial consultation, N (%)		
0–17 years	21 (23.1)	20 (54.1)
18–34 years	42 (46.2)	16 (43.2)
35–49 years	10 (11)	1 (2.7)
50 years or older	18 (19.8)	0
Etiological diagnosis known, N (%)		
Yes	31 (34.1)	33 (89.2)
No	60 (65.9)	4 (10.8)

Reasons for initial consultation

Consultation visit group (CV group)

The categorization of reasons for initial consultation shows that patients in the CV group most often had a psychological reason for initial consultation (45.1%) (Table 4.2) Regarding psychological reasons for initial consultation, 40% of the referrals concerned behavioural problems. Most found medical reasons were Musculoskeletal (21.4%), Neurological (17.9%), and Digestive (14%). In 22% of the CV group, having an ID was the only reason for initial consultation without an additional question. Of the patients in the CV group, 68.1% had a single type of reason for initial consultation: either medical, psychological, or context-related. When multiple types of reasons for initial consultation were present (9.9% of the cases), this always concerned a psychological reason combined with another type of reason for initial consultation.

Health check group (HC group)

The most prevalent reason for initial consultation in the HC group was a health assessment (81.1%). The rest of the HC group had additional reasons for initial consultation during their health assessment appointment: 10.8% had medical reasons, 5.4% had psychological reasons, and 2.7% had context-related reasons.

Table 4.2 Reasons for initial consultation of patients referred by a medical professional (CV group)

Type of reasons, N (%)	**N = 91**
Psychological reasons	41 (45.1)
Medical reasons	19 (20.9)
Context-related reasons	2 (2.2)
Psychological and medical reasons	4 (4.4)
Psychological and context-related reasons	5 (5.5)
Unspecified intellectual disability related reasons	20 (22)

Health-related problems identified during initial consultation

Consultation visit group (CV group)

Table 4.3 shows the type of health-related problems identified during initial consultation. For 71.5% of the patients in the CV group, two or three types of health-related problems were identified during initial consultation. This primarily involved medical and psychological problems, in respectively 78.0% and 73.6% of the cases. The most prevalent single type of problems identified during initial consultation were medical problems (17.6%).

Health check group (HC group)

Table 4.3 shows that for 83.8% of the patients in the HC group, medical, psychological, and/or context-related problems were identified during the initial consultation. In 45.9% of the patients, this involved a single type of problem. In 72.9% of the patients, medical problems were identified. Psychological problems were identified in 45.9% of the patients. For the remaining 16.2% of the patients in the HC group, no specified health-related problems were identified during initial consultation.

Table 4.3 Health-related problems identified during initial consultation

Type of health-related problems identified, N (%)	CV group N = 91	HC group N = 37
Medical, psychological, and context-related problems	27 (29.7)	1 (2.7)
Medical and psychological problems	23 (25.3)	12 (32.5)
Medical problems	16 (17.6)	13 (35.1)
Psychological and context-related problems	10 (11)	0
Psychological problems	7 (7.7)	4 (10.8)
Medical and context-related problems	5 (5.5)	1 (2.7)
Unspecified intellectual disability related problems	2 (2.2)	6 (16.2)
Context-related problems	1 (1.1)	0

Pattern between reasons for initial consultation and health-related problems identified during this consultation for the CV group

Table 4.4 contrasts the reasons for initial consultation with the three types of health-related problems identified during initial consultation for the CV group. For 72.6% of the CV patients who visited the outpatient ID practice for one type of reason, additional types of problems were identified during initial consultation. For 83% of the patients with only psychological reasons for initial consultation, additional problems were identified during initial consultation. In contrast, for half of the patients with only medical reasons for initial consultation (52.6%), only medical problems were identified during initial consultation. For the majority of the CV group patients who consulted the practice without a specified reason (90%), medical, psychological, and/or context-related problems were identified during initial consultation.

Table 4.4 Combining reasons for initial consultation and health-related problems identified during initial consultation of the CV group

			Health-related problems identified during initial consultation, N (%)								
			1 type of problem			2 types of problems			3 types of problems	unspecified problems	total
			med	psy	con	med & psy	med & con	con & psy	con, psy & med		
Reason for initial consultation, N(%)	**1 type of reason**	**med***	10 (52.6)	0	0	3 (15.8)	2 (10.5)	0	4 (21.1)	0	19 (100)
		psy†	0	7 (17.1)	0	10 (24.4)	0	8 (19.5)	16 (39)	0	41 (100)
		con‡	0	0	0	0	0	0	2 (100)	0	2 (100)
		total	17 (27.4)			23 (37.1)			22 (35.5)	0	62 (100)
	2 types of reasons		0	0	0	4 (100)	1 (20)	2 (40)	2 (40)	0	9 (100)
	unspecified reasons		6 (30)	0	1 (5)	6 (30)	2 (10)	0	3 (15)	2 (10)	20 (100)

*med=medical

†psy=psychological

‡con=context-related

Disciplines involved after initial consultation

The initial consultation led to the involvement of 25 professionals besides the ID physician for referral, assistance or treatment, and examinations (see Table 4.5). Involvement of disciplines occurred most often for the CV group and often concerned a GP (for 35.2% of the patients), a behavioural expert (34.1%), or a clinical geneticist (28.6%). Within this group, an average of two disciplines are involved per patient after initial consultation at the outpatient ID practice.

Table 4.5 Disciplines involved after initial consultation, arranged according to prevalence in the CV group

Involved disciplines, N (%)	**CV group N = 91**	**HC group N = 37**
General practitioner	32 (35.2)	3 (8.1)
Behavioural expert/Psychologist	31 (34.1)	2 (5.4)
Clinical geneticist	26 (28.6)	6 (16.2)
Neurologist	11 (12.1)	1 (2.7)
Rehabilitation physician	7 (7.7)	2 (5.4)
ENT doctor	5 (5.5)	1 (2.7)
Psychiatrist	5 (5.5)	0
Speech therapist	5 (5.5)	0
Nutritional expert	5 (5.5)	0
Eye expert	4 (4.4)	3 (8.1)
Dentist	4 (4.4)	3 (8.1)
Paediatrician	4 (4.4)	1 (2.7)
Internist	3 (3.3)	1 (2.7)
Gynaecologist	3 (3.3)	1 (2.7)
Orthopaedic surgeon	3 (3.3)	0
Epileptologist	3 (3.3)	0
Physiologist/Physiotherapist	2 (2.2)	1 (2.7)
Sexologist	2 (2.2)	0
Gastroenterologist	1 (1.1)	1 (2.7)
Dermatologist	1 (1.1)	1 (2.7)
Neuropsychologist	1 (1.1)	0
Urologist	1 (1.1)	0
Cardiologist	1 (1.1)	0
Occupational therapist	1 (1.1)	0
Endocrinologist	0	3 (8.1)

Discussion

This study is the first to explore the characteristics of specialized medical care for people with ID provided at a specialized outpatient ID practice. Results show that 1) patients often initially visit the outpatient ID practice for one type of complaint, most often psychological, 2) diverse, multiple, and interrelated health problems were identified during specialized medical ID consultation, and 3) a range of specialists professionals were involved by the ID physician. This highlights the value of specialized medical ID expertise and indicates a need for multidisciplinary approaches in the healthcare of people with ID.

Interpretation of findings

This study shows that people with ID often experience multiple and multifaceted health problems at the same time. The patient's history and context, in which ID is an underlying factor, plays a major role in adequately assessing health problems. It is essential to go beyond medical views and assess health complaints in an integrated way. This includes taking into account the way ID can influence all levels (physical, mental, contextual) of the experienced health issue within the context of everyday life. This is important, because ID, related co-morbidities, and the patient's context can influence the expression of symptoms, which can complicate the diagnostic process and treatment of various other medical and psychological problems. These problems might go unnoticed if the focus is on just the ID or on a specific medical or behavioural problem, risking over-, under- or misdiagnosis and -treatment [24]. Despite the broad focus on medical, psychological, and context-related issues, GPs have acknowledged to experience challenges in treating patients with ID [9, 14]. This study indicates that this is where specialized medical ID expertise, such as provided by ID physicians, can make a difference in improving healthcare for this patient group.

Professionals with specialized medical ID expertise, such as ID physicians, are of value in assessing health complaints in a holistic way, including the specific multimorbidity of people with ID, their context, special medical and psychological care needs, and the aetiology of ID [22]. This expertise can be seen as complementary to the expertise of the GP. Effective collaboration between both professionals will help improving the healthcare as well as reducing the burden on either profession [25]. The referral reasons of the CV group indicate that GPs often refer to specialized ID physicians in the case of psychological problems, which frequently concern behavioural problems, suggesting that GPs especially encounter challenges in assessing these problems in people with ID. Dutch GPs are not always aware that they can refer to specialized ID physicians when facing these challenges. Patients were also referred to the outpatient ID practice without specification of a reason other than having ID. This could be because GPs often suspect that ID play a role in patients' health complaints, but do not know in what manner. A qualitative follow up study can investigate this further.

A possible explanation for the referral reasons being narrower than the problems identified during initial consultation could be that problems are overlooked or 'diagnostically overshadowed' by the ID [24, 26, 27]. This concerns the tendency to address symptoms primarily to the ID, which might contribute to missed diagnoses. Misunderstandings on how a person with ID expresses themselves, or reacts to stress, overburdening, and overstimulation might result in incorrect diagnoses as well. Physicians without specialized ID expertise may not always recognize the presence of ID in their patients since this is often not registered or may not know the multiple ways in which an ID can influence the presentation of health-related problems. This increases the risk of misdiagnosing complaints and applying diagnostic processes and treatments that are not tailored to the patient with ID [28].

This study identified 25 different healthcare professionals that can be involved for referral, assistance, examinations, or treatment, which indicates a significant need for combined expertise in providing medical care for people with ID [20]. This is indicative for the need of multidisciplinary approaches in the healthcare of people with ID [29]. The broad range of healthcare professionals that people with ID can encounter makes it imperative that mainstream professionals are equipped with some basic tools and skills to provide effective and compassionate care for this population. Awareness that ID can cause different presentations of health problems, that people with ID have complex medical care needs, and that the expertise of specially trained medical professional is available would help both patients with ID and healthcare professionals. Furthermore, medical professionals should be able to recognize a patient with ID. This can be included in both pre- and postgraduate training for medical and paramedical professionals. Furthermore, teaching medical professionals about how to assess the combination of medical, psychological, and context-related problems and how ID can be the underlying interaction in this interplay.

Strengths and limitations

This study used routinely collected data at the outpatient ID practice that was not collected for research purposes specifically. This resulted in two limitations.

Firstly, the registration was not fully standardized, leading to missing or inadequately registered data. Secondly, a GP system was used that did not allow for registration of multiple reasons for consultation and did not include ID-specific codes for registered reasons of consultation. These items were added by the ID physicians in free text clinical notes and included in our data as described in the Methods section. This allowed us to obtain better insight in consultations and gave a first idea about what specific ID-related codes could be helpful to add in future development of the registration system. The manual coding of clinical entries on health-related problems identified during initial consultation in terms of broader categories (medical, psychological, context-related) limited insights into the specifics of these problems.

The start of the COVID-19 pandemic challenged obtaining retrospective informed consent, which impacted the number of patients that could be included. Consequently, this study's findings are based on 24.3% of the patients who visited the outpatient ID practice before the extraction date. The sex and age distribution in this study's population is representative of the total patient population at the outpatient ID practice, but limitations in data about the ID population make it difficult judge the generalizability of our results.

This study has been performed in the Netherlands, and it is important to acknowledge that the findings might not be directly applicable to other countries. Despite this limitation, the Dutch setting provided a unique opportunity to explore the value of specialized medical ID expertise and gave insight in the often multifactorial undiscovered health-related problems that people with ID encounter.

Conclusion

This study illustrates the role of specialized ID expertise in medical care for people with ID. Having ID impacts a person's life beyond their health in multiple areas that can in turn affect health as well. Specialized medical ID expertise helps to assess health problems of people with ID in the broader context of a patient's everyday life. Physicians or nurses specialized in ID can help to adequately assess the combination of medical, psychological, and context-related problems that can be easily overlooked in people with ID. Additionally, this study shows that specialized medical ID expertise is of value in organizing multidisciplinary care for people with ID. Examining specialized medical ID consultations provided the opportunity to learn about the complex health-related problems of people with ID.

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Appendix

Supplementary File S4.1 Easy-to-read information letter in Dutch

Informatiebrief over onderzoek
De zorg van de AVG arts

Je ontvangt deze brief omdat je de AVG arts (arts voor verstandelijk gehandicapten) in Nijmegen hebt bezocht.
Je kunt iemand om hulp vragen om samen met je de brief te lezen.


Esther


Marian

Hallo, ik ben dokter Esther Bakker-van Gijssel.
Ik ben een AVG arts.
Ik doe ook onderzoek
Dit doe ik samen met andere onderzoekers, zoals Marian Breuer.
Wil je meedoen aan onderzoek?
Deze brief helpt je om te kiezen.

Waar gaat het onderzoek over?

Het onderzoek gaat over de zorg van de AVG arts in Nijmegen.
Dit is een dokter die mensen met een verstandelijke beperking goed kan helpen.
Voor dit onderzoek wordt informatie die de dokter over jou bijhoudt op de computer gebruikt.

Wat moet jij doen?

Om naar jouw informatie te kijken, heb ik je toestemming nodig.
Hiervoor moet je 2 formulieren invullen en ondertekenen.
Jij hoeft verder niks te doen.
Ik kan jouw informatie en die van andere patiënten bekijken.
Ik zal dit met veel aandacht doen.
Niemand weet dat het over jou gaat.
Als het onderzoek klaar is, wordt er een verslag geschreven.
Jouw naam komt hier niet in te staan.

Wat zijn de afspraken als je meedoet?

Als je mee wil doen, help je mij.
Zo kunnen we de zorg van de AVG arts beter maken.
Meedoen kost jou geen tijd.
Meedoen heeft geen voordeel voor jou.
Je mag zelf kiezen of je meedoet.
Als je niet meedoet, verandert er niks aan je behandeling van de AVG arts.

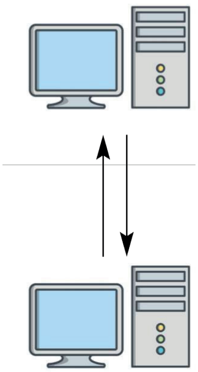
Sterker Op
Eigen Benen

Radboudumc

Je mag altijd stoppen met meedoen aan onderzoek.
Als je wilt stoppen of een vraag hebt, mag je de AVG-arts bellen of mailen.
Ook na het onderzoek mag je de informatie die we over jou opslaan, opvragen als dat nodig is[2].

Waar geef je toestemming voor?

Je kan toestemming geven voor 4 dingen.
Je hoeft niet voor alles toestemming te geven.
Je kan zelf kiezen voor welke dingen je toestemming geeft:



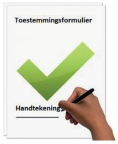
1. De arts houdt informatie over jou bij op de computer. Deze informatie gaat over jou (bijvoorbeeld je leeftijd), waarom jij de AVG arts bezoekt en wat de AVG arts doet. Mag ik die informatie gebruiken om onderzoek te doen?

2. Er zijn ook andere mensen die informatie bijhouden over jouw gezondheid, bijvoorbeeld de huisarts. Met deze informatie kan ook onderzoek worden gedaan. Mag ik die informatie gebruiken om onderzoek te doen?

3. Het CBS[1] verzamelt heel veel informatie over alle Nederlanders. Mag ik de informatie over jou van het CBS gebruiken om onderzoek te doen?

4. Mag ik jou later nog een keer vragen om mee te doen aan wetenschappelijk onderzoek?

Doe je mee?



Dan vul je dit in op 2 toestemmingsformulieren.
Deze 2 formulieren heb je ook gekregen.
Vul je voorletters, achternaam en geboortedatum in.
Iemand mag je daarbij helpen.
En onderteken het formulier.
Soms moet de wettelijk vertegenwoordiger dat doen.
Dat kan je aan hem of haar vragen.
1 formulier mag je zelf houden.
En 1 formulier doe je in de antwoord-envelop en op de post.
Je hoeft geen postzegel op de envelop te plakken.

---

[1] Het CBS (Centraal Bureau voor de Statistiek) verzamelt heel veel informatie over alle Nederlanders.

[2] Deze rechten op inzage, rectificatie en ontvangen van persoonsgegevens staan beschreven in de Algemene verordening gegevensbescherming

Supplementary File S4.2 Easy-to-read informed consent form in Dutch

Toestemmingsformulier
De zorg van de AVG arts

Op dit formulier vul je in of je mee wilt doen aan onderzoek naar de zorg van de AVG arts.
Je kunt iemand om hulp vragen om samen met je het formulier te lezen en je handtekening te zetten.

Ik heb de informatiebrief over het onderzoek gelezen.
Ik heb de onderzoeker vragen kunnen stellen.
Mijn vragen zijn beantwoord.
Ik heb genoeg tijd gehad om na te denken of ik mee wil doen.

Ik weet dat meedoen vrijwillig is.
En dat ik op ieder moment kan stoppen zonder dat ik hoef te vertellen waarom.

Ik weet dat de informatie over mij wordt bewaard op een veilige plek.
De mensen die de documenten mogen bekijken zijn:

- Onderzoeksteam
- Mensen die het onderzoek controleren

Ik geef toestemming voor:
1. Het gebruiken van informatie die is verzameld door de AVG arts in Nijmegen.
O ja O nee

2. Het gebruiken van informatie over mijn gezondheid die is verzameld door andere mensen, zoals de huisarts.
O ja O nee

3. Het gebruiken van informatie over mij van het CBS[1].
O ja O nee

4. Later nog een keer gevraagd te worden om mee te doen aan wetenschappelijk onderzoek
O ja O nee

[1] Het CBS (Centraal Bureau voor de Statistiek) verzamelt heel veel informatie over alle Nederlanders.

Ondertekening door patiënt en/of wettelijk vertegenwoordiger

Achternaam en voorletters patiënt:

Geboortedatum patiënt:

Handtekening patiënt:	Datum van tekenen:

Handtekening wettelijk vertegenwoordiger:	Datum van tekenen:

Ondertekening door AVG arts

Ik verklaar hierbij dat ik de patiënt en/of wettelijk vertegenwoordiger volledig heb geïnformeerd over onderzoek over de zorg van de arts voor verstandelijk gehandicapten.

Naam AVG arts:

Handtekening AVG arts:	Datum van tekenen:

Heb je vragen?
Mail naar: info@avgpraktijknijmegen.nl
Of bel de AVG praktijk via: 088-7795002

Supplementary Table S4.1 Summary of variables

Variable group	Variable
1. Demographics	Sex Age at initial consultation Age at initial consultation divided into 4 groups Number of consultations during year of initial consultation Etiological diagnosis known
2. Reason for initial consultation	Reason for initial consultation in ICPC-2 codes Reason for initial consultation categorised in 3 types: medical, psychological, or context-related, or combinations of these types (see Supplementary Table S4.2 for procedure)
3. Health-related problems identified during initial anamnesis	Health-related problems categorised in 3 types: medical, psychological, context-related, or combinations of these types
4. Disciplines involved after initial consultation	Disciplines involved after initial consultation in written text, identified using multiple syntax searches

Supplementary Table S4.2 Operationalizations and examples of medical, psychological, and context-related problems related to diagnostic codes.

Category	Examples	Including minimally one of the following ICPC codes:
Medical	Problems related to the digestive system, cardiovascular system, nervous system, urinary tract system. Problems with skin, ears, or eyes.	A03 B01-29 & B70-99 D01-29 & D70-99 F01-29 & F70-99 H01-29 & H70-99 K01-29 & K70-99 L01-29 & L70-99 N01-29 & N70-99 R01-29 & R70-99 S01-29 & S70-99 T01-29 & T70-99 U01-29 & U70-99 W01-29 & W70-99 X01-29 & X70-99 Y01-29 & Y70-99
Psychological	Behavioural problems Depressive feelings Sleep problems	P01-29 & P70-84 & P86-99 Behavioural = P01, P04, P22, and P23
Context-related	Problems with work, housing, or social contacts Problems related to the death of another person	Z01-29 & Z70-99
Unspecified ID related	Pain, fatigue, feeling ill	Codes 30-69 in all ICPC-2 categories P85 A01-99, excluding A03

Chapter 5

The role of specialized medical ID expertise in care consultations for people with intellectual disabilities: experiences of caregivers and patients

Under review: Breuer, M. E. J., Bakker-van Gijssel, E. J., Pelle, T., Naaldenberg, J., Leusink, G. L. (2024). The role of specialized medical ID expertise in care consultations for people with intellectual disabilities: experiences of caregivers and patients. Journal of Applied Research in Intellectual Disabilities.

Abstract

Background This study aims to explore patients' and their caregivers' experiences with, and expectations of, a medical consultation with a specialized ID physician at an outpatient ID practice.

Methods Fifteen semi-structured interviews were conducted with patients and their caregivers. Interview topics concerned 1) ID physician's knowledge and skills, 2) communication between participants and ID physician, and 3) coordination between ID physician and other professionals.

Results Seven themes addressing roles of the ID physician were identified. Five roles relate to actions and attributes during medical consultations: clinician, patient-centred doctor, holistic physician, human, and sparring partner for the patient's network. Two roles relate to actions and attributes around medical consultations: coordinator and advocate.

Conclusions Patients with intellectual disabilities and their caregivers value ID physicians' roles beyond clinical skills during consultations, including roles related to care coordination, having a professional network, and advocating in a broader context around medical consultations.

Background

The health disparities and healthcare inequities experienced by people with intellectual disabilities are widely recognized [1-4]. People with intellectual disabilities have different morbidity patterns and experience more comorbidity and syndrome-related health problems compared with the general population [5, 6]. Furthermore, they experience challenges in receiving appropriate medical care, such as communication barriers, negative staff attitudes and behaviour, problems with accessing services, and lack of support and involvement of carers [7, 8]. Consequently, people with intellectual disabilities experience challenges in access to quality and effective medical care [2].

The availability of specialized medical ID expertise has been suggested to improve medical care for people with intellectual disabilities [2, 9-12], but studies exploring the value of specialist medical ID services for facilitating access to medical care services are scarce [13]. The Netherlands has specialized physicians who provide medical care for people with intellectual disabilities. These physicians complete a three-year vocational post-graduate training course in ID-specific medical knowledge and skills [14]. The core competencies of the ID physician include knowledge of the aetiology and consequences of intellectual disabilities and associated health problems [15]. The ID physician also knows how to deal with ID-related diagnostic and therapeutic challenges [15]. ID physicians work predominantly in care organization settings, but there are also outpatient practices where ID physicians work. General practitioners (GPs) or medical specialists can refer patients with intellectual disabilities to these practices when ID-specific medical expertise is required [14].

As with healthcare in general, the value of specialized medical ID care is linked to the experiences and expectations of the patients themselves [16-18]. The patient experience is globally recognized as an independent dimension of health-care quality [19]. Studies focusing on qualities that are deemed desirable in physicians have been performed previously to improve medical care [20-24]. Shifting the focus from the obstacles and barriers that patients face to highlighting and enhancing desirable attributes of medical care professionals reinforces a patient-centred approach in which the patients' needs are the driving force behind their medical care [25]. Although the barriers to appropriate medical care for people with intellectual disabilities have been extensively mapped in the literature [7, 8, 11, 26], studies on desirable qualities for medical care professionals from the perspective of patients with intellectual disabilities are largely lacking [27]. To provide insight in the caregivers' and patients' perspective, this study explores their experiences with, and expectations of, a medical consultation with a specialized ID physician at an outpatient ID practice.

Methods

Study design

Fifteen semi-structured face-to-face duo or trio interviews were conducted with patients of the outpatient ID practice in Nijmegen, the Netherlands, and their caregivers. Interviews lasting between 40 and 70 minutes were performed by a researcher (MB, female, trained in qualitative research methods) and a research assistant – both of whom were knowledgeable about the setting of the outpatient ID practice – between May and August 2023 in a location of participants' choice. Interviewees and interviewers had no prior relationship. Interviews were audio-taped with the participants' permission, transcribed verbatim, and anonymized. The results are reported according to the consolidated criteria for qualitative research (COREQ) [28].

Participants

People with intellectual disabilities (≥18 years) who visited the outpatient ID practice in Nijmegen and the person(s) who accompanied them to the consultation (i.e., their informal or professional caregivers) participated in this study. The outpatient ID practice in Nijmegen provides specialized medical care for patients with intellectual disabilities who live in the community, and either are referred by the GP for a specific health-related problem or visit the outpatient ID practice for proactive health checks related to the etiological diagnosis of their ID. People with intellectual disabilities visit the outpatient ID practice accompanied by a professional or informal caregiver. These caregivers are essential participants in the consultation at the patient's side and were therefore interviewed as well. In this study, caregivers were two professional caregivers and 19 family members. Consequently, although the term caregivers is used, the results of this study apply mainly to the experiences of family members. A purposive sampling strategy was used to select participants that visited the outpatient ID practice between April and August 2023 and were minimally 18 years old. Purposive sampling is a technique used in qualitative research to select a specific group of individuals or units for analysis. Participants are chosen "on purpose", not randomly. Easy-to-read information letters and informed consent forms were distributed at the end of consultations by the ID physicians working in the outpatient ID practice in Nijmegen or via email (see Supplementary Files S5.1 and S5.2). Both documents were developed with the help of a co-researcher with intellectual disabilities. The persons who expressed interest to participate were contacted by telephone by the interviewer (MB), who provided them with further information about the interview and who answered their questions. The legal representative could sign the informed consent form on behalf of the patient in the case of moderate to severe intellectual disabilities. After informed consent was obtained, the interview was scheduled.

Data collection

Interviews took place between May and August 2023 in a setting of participants' choice (most often their home) and lasted between 40 and 70 minutes. Interviews were conducted by a trained interviewer (MB) and a research assistant who helped summarizing the interview by taking notes on post-its during the interview. Interviews focused first on the experiences of patients, complemented by the caregivers' experiences instead of the ideas of experts that are found in existing literature. Caregivers were encouraged to support the patients in answering the questions and elaborating on experiences, but not to speak for them. The interview guide (Table 5.1) was created in collaboration with a co-researcher with intellectual disabilities and pilot tested in three pilot interviews with persons with intellectual disabilities. To help interviewees in recalling the medical consultation, they were supported with photographs that illustrated the visit to the outpatient ID practice (i.e., the entrance, the waiting room, the physician). The interviews followed the chronology of the visit and focused on the following topics: 1) ID physician's knowledge and skills, 2) communication between participants and ID physician, and 3) coordination between ID physician and other care providers. These topics were based on the competence profile of ID physicians [29] and previous studies investigating aspects of medical care for people with intellectual disabilities [9, 30]. To allow interviews to capture experiences beyond the idea of a consultation being positive or negative and help interviewees to think about what adds value to their medical care, the interviews followed an appreciative inquiry approach [31]. Using this approach obviated the compilation of a list of problems that were already known and allowed for identifying and building on the strengths, successes, and values of specialized medical care consultations for people with intellectual disabilities [32].

At the end of the interviews, the experiences as described by patients and their caregivers were summarized by the interviewer, ensuring that they were understood correctly and that no significant experiences were missed. Data saturation was reached with 15 interviews, when no new themes were introduced during the interviews. The interviewer's notes and reflections formed part of the dataset.

Table 5.1 Summary of the interview guide

Focus	The interview guide focused on interviewees' experiences with a recent specialized medical care consultation for people with intellectual disabilities. The first prompting question was: 'Could you tell me something about your recent consultation at the outpatient ID practice in Nijmegen?'
General	Interviewees were invited to talk about what they liked about the consultation at the outpatient ID practice by the question: 'What did you like best about your ID physician?'
Topic 1: ID physician's knowledge and skills	Interviewees were prompted to reflect on the ID physician's knowledge and skills. Illustrative examples of questions asked include: 'What should a good ID physician know?' and 'What did you like about what the ID physician did?'
Topic 2: Communication between patient/ support person(s) and ID physician	Interviewees were prompted with an opening question to reflect on what they liked about the conversation with the ID physician. An illustrative example of a more specific question asked is: 'Can you give me an example of when the ID physician communicated well with you?'
Topic 3: Coordination between ID physician and other care providers	Interviewees were asked to reflect on the coordination between their ID physician and other care providers such as their GP. An illustrative example of a question asked is: 'Can you tell me about a situation in which your ID physician has worked well together with other healthcare professionals?'
Additional questions	Interviewees were asked about differences in their experiences with medical care provided by ID physicians and other medical care providers (e.g., GPs or medical specialists). Additionally, they were asked to think of tips for physicians in general when dealing with a patient with intellectual disabilities.

Data analysis

Data were analysed thematically by four researchers with different backgrounds, including one ID physician, supported by ATLAS.ti software version 23.1.1 [33]. The iterative analysis phases are described in Table 5.2. In phase 1, the transcripts were read to obtain a general understanding of the data. Respondents described ID physicians' roles, activities, and attributes during or outside specialized medical care consultations. In phases 2 and 3, the transcripts were coded by two researchers using an inductive approach, distinguishing between experiences with ID physicians during or outside consultations. Coding results were discussed, and codes were reassigned, combined, or divided. In phase 4, the codes were compared, contrasted, and grouped based on commonalities among the codes and labelled into seven themes.

Table 5.2 Iterative analysis phases

Phase	**Action**	**Result**
1. Reading the transcripts	Reading all 15 transcripts to obtain a general understanding of the data	-
2. Assigning open codes to fragments of transcripts	Assigning open codes iteratively to three transcripts by two independent researchers (MB, TP). Discussing codes and discrepancies to reach consensus on a coding scheme (MB, TP).	Coding scheme distinguishing between experiences during or after consultations
3. Applying coding scheme to all transcripts	Applying the coding scheme to the remaining transcripts (MB). Discussing coding results (MB, TP) and reassigning, combining, or splitting up codes (MB).	15 coded transcripts
4. Grouping codes and labelling groups	Grouping and reorganizing codes, through iterative discussion, into categories that have commonalities (MB, TP, EB, JN). Labelling groups using ID physicians' roles mentioned by the interviewees or devised by the research team based on commonalities of the codes (MB, TP, EB, JN).	7 labelled groups with related codes

Results

Participant information

We interviewed six patients, 19 informal caregivers, and two professional caregivers. In nine interviews, patients were excluded for various reasons provided by caregivers, including patient cannot speak, patient cannot provide answers to the interview questions, or taking part in an interview is too stressful for patient. Patients were often not able to reflect on their experiences in an extensive and in-depth manner, necessitating the support of their caregivers.

Seven themes

Analysis resulted in seven themes that address the ID physician's roles. Five roles relate to the ID physician's actions and attributes during medical consultations: clinician, patient-centred doctor, holistic physician, human, and sparring partner for the patient's network. Two roles relate to the ID physician's actions and attributes around medical consultations: coordinator and advocate. Table 5.3 presents the activities and attributes related to a particular role.

Table 5.3 Roles of ID physician with accompanying activities and attributes, according to patients with intellectual disabilities and their caregivers

	Roles	Activities and attributes
Roles during medical consultation	Clinician	• Providing lifelong treatment for complaints related to ID or syndromes • Having knowledge of, and experience with, people with intellectual disabilities, their complaints, syndromes, and the medication they use • Providing ID-related information to patients and their support persons • Focusing on prevention (health assessment) • Performing a complete medical scan of patients • Providing medication after strict assessment • Deviating from standard medical protocols
	Patient-centred doctor	• Connecting with patients • Communicating with patients instead of about patients/ Focusing on self-reporting (vs. proxy reporting) • Adapting communication level to patients • Explaining beforehand what is going to happen to patients
	Holistic physician	• Recognizing the interconnectedness of physical, social, and environmental contributors to health • Preparing the consultations • Providing insight into new possibilities • Paying attention to patients' signals • Breaking up complex problems into smaller components
	Human	• Creating an environment in which patients and their support persons feel confident to express their feelings and tell their story • Bringing peace by taking time during consultations • Having a friendly appearance
	Sparring partner for the patient's network	• Including caregivers' vision and ideas • Including caregivers in communication during and after consultation • Being a sparring partner for caregivers • Providing tips and advice for caregivers • Having good communication skills
Roles around medical consultation	Coordinator	• Organizing and overseeing patients' care activities • Sharing information among all professionals concerned with a patient's care • Having a broad network of medical care professionals • Acknowledging the limits of their own capabilities • Creating a logical and practical plan of follow-up steps
	Advocate	• Shielding patients from unnecessary treatments and consultations • Being someone with a voice to accomplish change outside consultations • Being decisive and confident

Themes during medical consultation

1. Clinician

Interviewees experienced and expected that ID physicians have knowledge of, and experience with, people with intellectual disabilities, their complaints, syndromes, and medication. ID physicians use this knowledge and experience to perform clinical activities, thereby providing lifelong medical treatment for people with intellectual disabilities.

> *She [ID physician] understood a lot and had a lot of experience, you notice that immediately, also with these kinds of complaints. I thought it was a very nice consultation.* (Int 2, professional caregiver)

ID physicians' focus on prevention, and their extensive medical assessments of patients were appreciated by interviewees, because that can prevent complex problems and the associated burden on patients and their family and lower costs of care. Furthermore, ID physicians provided medication only after strict assessment; the interviewees appreciated this, because they prefer a more permanent solution to problems than medication.

> *Luckily there was no rush to medication. The first thing was: let's see if it is necessary at all.* (Int 3, informal caregiver)

ID physicians also provide ID-related information to patients and their caregivers, providing them with guidance and understanding concerning ID. To support the provision of adequate medical care for people with intellectual disabilities, ID physicians are allowed to deviate from standard medical protocols if substantiated, because these are often not fully suitable for patients with intellectual disabilities.

> *Also, colour a little outside the lines sometimes. That doesn't kill anybody at all, and you help people with that.* (Int 14, informal caregiver)

2. Patient-centred doctor

ID physicians focus on patients' self-reporting and on adapting their communication to the patients' needs and level of understanding, thus contributing to the involvement of patients with intellectual disabilities during medical consultation. However, ID physicians take into account that patients with ID are not always able to properly understand or answer health-related questions. Therefore, caregivers should be included in communication to complement the information provided by patients.

> *Really involve the patient as well, and not just talk about someone.* (Int 3, informal caregiver)
>
> *She [ID physician] always wants to know from the patient as well: hey what's your story? Then we always want to keep our mouths shut as much as possible, as we want the person to tell themselves first. But when you notice that some information is missing, it is heartening that we can complement the patient. That she [ID physician] gives us that space.* (Int 4, professional caregiver)

Taking time and explaining beforehand what the ID physician is going to do is appreciated, because this ensures that patients are willing to cooperate with tests and physical examinations. However, the amount of information provided can also be overwhelming for patients.

> *ID physicians know how to work with persons with a disability, so the way of approaching was very safe for her [patient]. So that all went very pleasantly. The ID physician was able to examine everything and she [patient] was very calmly lying on the treatment table. That went very calmly.* (Int 11, informal caregiver)
>
> *She can explain well, but it was a lot of information. It made me think what the hell are you talking about.* (Int 7, patient)

3. Holistic physician

ID physicians view the medical complaints of patients with intellectual disabilities within the patients' context and history to adequately address the patients' help request. They recognize the interconnectedness of physical, social, and environmental contributors to health. Because ID physicians have an overall view on patients' complaints, they often provide insight into new possibilities.

> *There was a total approach to [patient] as a human being, that was also mindful of her environment but also the medical part. It was all complete and balanced. Therefore, it exceeded our expectations.* (Int 11, informal caregiver)

To support a holistic perspective on the patient, ID physicians prepare medical consultations, pay attention to patients' signals to understand how a patient indicates when something is wrong, and split up complex problems to smaller components to get to the solution faster and bring peace for patients and their support persons. Not all caregivers experienced that the ID physician was fully prepared for the consultation.

> *An ID physician can only use the pieces of information that she has. If she had said beforehand that she wanted more information, then the conversation would have gone a little easier.* (Int 8, informal caregiver)

4. Human

ID physicians act not only as physicians but also as human beings during medical consultations. They create an environment in which patients and their caregivers feel confident to express their feelings and tell their story. ID physicians do this by taking their patients seriously, being respectful, and taking time for medical consultations. ID physicians are kind, friendly, sympathetic, and empathic and show a genuine interest in their patients.

> *I must say that she [ID physician] takes us seriously and she treats the people who visit her very respectfully.* (Int 4, professional caregiver)

A friendly environment is created by making jokes, connecting with the patient, and taking time. Also, ID physicians with a friendly appearance make the interviewees feel comfortable during consultations.

> *[Patient] felt relaxed. He is a sensitive boy, so he picks up tension easily. You have to be careful not to rush* (Int 2, professional caregiver)
>
> *Her [ID physician's] appearance gives me confidence* (Int 4, patient)

5. Sparring partner for the patient's network

ID physicians collaborate with caregivers during medical consultations to provide appropriate medical care for people with intellectual disabilities. The caregivers noticed that the ID physician did not only see the patient, but also the caregiver as a sparring partner. Caregivers play a supporting role to both patients and medical professionals because they know the patient well. Caregivers can for instance help articulating the patient's complaints and they have a broader understanding of the patient's context than the medical professional. The caregiver's knowledge of the patient and the ID physician's clinical knowledge is combined during medical consultations. Caregivers appreciated ID physicians' inclusion of their vision and ideas during the consultation. As a sparring partner, the ID physician is someone to whom caregivers can present an issue, idea or thought related to the patient. The ID physician asks questions and thinks along, but the responsibility for the issue remains with the caregiver. In this way, ID physicians can offer tips and advice for caregivers.

> *She [ID physician] provides tips for us as supervisors, like: how can you best deal with this, what is useful and what not? […] She strengthens us in our actions, so that's nice.* (Int 4, professional caregiver)

To support good collaboration between ID physicians and caregivers, ID physicians have good communication skills. This includes listening, asking follow-up questions, and providing clear explanations.

> *The way of communicating. I think they [ID physicians] are more focused, trained, and experienced in that.* (Int 1, informal caregiver)

Themes around medical consultation

6. Coordinator

Interviewees appreciated ID physicians taking charge of patients' medical care outside medical consultations. ID physicians organize and oversee all patients' care activities and create a logical and practical plan of follow-up steps. The caregiver's workload can be lowered by the physician taking over coordinating tasks.

> *She [ID physician] is ultimately the one who runs the whole thing. […] Such a person has a better view than we do of what is possible in the medical circuit […] and what the options are and where you should go [to make use of these options].* (Int 8, informal caregiver)

Caregivers did not always experience these coordinating activities in ID physicians.

> *I still feel like I have to keep control and I don't want that at all.* (Int 13, informal caregiver)

Having a broad network of medical care professionals is part of ID physicians' coordinating activities. Access to such networks ensures that all parties involved in patients' care are up to date on relevant developments and are involved at the appropriate time. A prerequisite for this is that ID physicians know and acknowledge the limits of their own expertise, meaning that they refer to more appropriate professionals when needed.

> *All the different medical agencies are very much fragmented, so he [patient] falls in between them. They [the agencies] do not collaborate and the ID physician has to spar in between. And she [ID physician] is trying really hard to do that.* (Int 10, informal caregiver)
>
> *ID physicians are humble: they also admit when they don't know something.* (Int 11, informal caregiver)

7. Advocate

ID physicians were described as innovators who take responsibility for change in the organization of care and support for people with intellectual disabilities. They can work to promote the rights, inclusion, and well-being of people with intellectual disabilities outside medical consultations and are perceived as someone with a voice to accomplish change.

> *It [people with intellectual disabilities] is a group that never stands up for itself. So, an ID physician might also be more likely to observe: would it be good if this or that was organized differently? It might be someone with a voice in the violence of the world of medical care.* (Int 1, informal caregiver)

ID physicians can, for example, shield patients from unnecessary treatments and consultations by acting as gatekeepers, authorizing patients' access to secondary and tertiary care.

> *She [ID physician] is kind of watching to see if it [treatment] makes sense or not. So, a bit of a gatekeeper. I have that view of an ID physician.* (Int 6, informal caregiver)

The ID physician requires the attributes of decisiveness and confidence.

> *I need someone who is just a strong person and says: this is how we are going to do it or this is what we have to do and that's what I need. The general practitioner was too insecure, so the ID physician took it over.* (Int 5, informal caregiver)

Not all caregivers experienced this decisiveness.

> *An ID physician should say: wait a minute. I have to take a closer look to see whether this can be done differently. But they just let us fool around.* (Int 15, informal caregiver)

Discussion

This study aimed to explore patients' and their caregivers' experiences with, and their expectations of, a medical consultation with a specialized ID physician at the outpatient ID practice. We identified seven themes that address the ID physician's roles that move beyond, and complement, themes identified in previous studies on people with intellectual disabilities [2, 34-36] and the general population [21, 22, 24]. Five roles relate to the ID physician's actions and attributes during medical consultations: clinician, patient-centred doctor, holistic physician, human, and sparring partner for the patient's network. Two roles relate to the ID physician's actions and attributes around medical consultations: coordinator and advocate.

The current study identified two roles that are also found in the literature concerning the general population: human and coordinator. Patients generally desire their doctors to possess personal attributes and behaviour, such as honesty, trust, politeness, and respect [22, 24, 37]. Furthermore, patients – irrespective of intellectual functioning – highlight doctors' need for medical management skills and organizational skills [21, 24]. The current study adds that these personal and coordinating characteristics are also valued by patients with intellectual disabilities and thus represent universal characteristics that are important to patients regardless of intellectual functioning.

The other identified themes represent characteristics that require specification for patients with intellectual disabilities in addition to the broader physician role as described by medical professional organizations globally, such as the CanMEDS framework [38]. This study specified the roles of an ID physician from a patients' and caregivers' perspective. Characteristics of the roles of Communicator and Collaborator resemble the themes 'Patient-centered doctor' and 'Sparring partner for the patient's network' as identified in this study. Our study describes these themes more specifically for people with intellectual disabilities and adds the important role that the ID physician can play in involving patients' caregivers in the medical care for people with intellectual disabilities. For example, ID physicians can use the caregiver's knowledge of managing the patient's health problems to provide appropriate care. Although patient involvement in medical care and decision making is generally seen as essential, for patients with intellectual disabilities this can be more complicated because of, for example, communication challenges, limited understanding of medical issues and limited body awareness [37, 39]. Our study shows that patients and their caregivers value involvement of both patients with intellectual disabilities and their caregivers and that the ID physician's skills help to overcome challenges in regular medical care in this regard.

In addition, our study adds that the role of Advocate is crucial for professionals in the medical care for people with intellectual disabilities, because having intellectual disabilities can make self-advocacy difficult [34]. This advocate role in the medical care for people with intellectual disabilities is broader than in general medical care, including standing up for patients with intellectual disabilities in the medical world and providing explanations about the patient group of people with intellectual disabilities to medical specialists. This advocacy role has also been identified for ID nurses [34]. A broad and holistic view is also described as a desirable quality of physicians in general [24]. The medical care for people with intellectual disabilities often entails complex medical problems and the risk of over- or under diagnosis and treatment, making this view an important feature in the delivery of medical care for this group [2]. Multiple studies have indicated that people with intellectual disabilities have complex healthcare needs and often experience co-morbidities [9, 36]. Therefore, existing guidelines for general population patients might not always apply to people with intellectual disabilities [40]. Our study indicates that, as part of specific clinical competence, ID physicians' ability to make informed decisions about deviating from guidelines, if substantiated, is valued by patients and helps to better tailor medical care to specific needs. Some of these roles also seem to be relevant for other vulnerable populations with complex care needs, such as patients with dementia [35]. Fortunately, there are now more and more guidelines relating specifically to people with intellectual disabilities [41].

Internationally, there are several ID-specialized medical professionals, such as ID nurses, who fulfil roles in the medical care of people with intellectual disabilities. A study by Doody, Hennessy [42] identified roles and responsibilities for ID nurses which are comparable to the ID physicians' roles identified in the current study, including their role in collaborating with patients and families and their leadership role in clinical care and coordination of services. ID nurses' ability to connect and relate to patients with intellectual disabilities, rather than their clinical skills, is described as unique for this profession [34]. Although there is an overlap in the roles of ID nurses and ID physicians, there are also differences in clinical competences and responsibilities. ID physicians have extensive knowledge of the medical problems and co-morbidities that are prevalent among people with intellectual disabilities and its relation with syndromes and medication. To optimize lifelong medical care for people with intellectual disabilities, nurses' and physicians' roles complement each other.

Strengths and limitations

During the interviews, participants were asked to reflect upon past consultations, and this might have caused recall bias, leading to inaccurate and incomplete information. To limit this bias, interviews were scheduled as close to the consultations as possible, and caregivers were encouraged to help patients in recalling the consultation. Although this study aimed to explore experiences with, and expectations of, specialized medical consultations, two themes reflecting roles of the ID physician outside of medical consultations were identified. This provides a novel insight in the influence of what happens surrounding the consultation on medical care as much as what happens within the doctor's office. A follow up study could build from this to further explore themes outside of consultations. When preparing the interview protocol in collaboration with experts by experience, the researchers added photographs of the ID physicians, the outpatient ID practice, and different moments in the consultation to stimulate remembering. Selection bias may have occurred because interviewees who volunteered to participate might have had stronger opinions and experiences related to the topic than those who did not volunteer. The use of appreciative inquiry allowed the interviews to span beyond experiences being positive or negative and focus on what adds value and what is important (either based on a positive or negative experience). While this approach starts from the positive, it does not ignore the negative and can even help to prevent interviewees feeling uncomfortable sharing negative experiences [32]. In line with other research projects [32, 43], this study yielded a nuanced understanding of both positive and negative experiences.

This study perceives patients and their caregivers together as the visitors to the outpatient ID practice, and their combined answers formed the data used in this study, resulting in a richer perspective than in studies in which only the patients or only the caregivers were included. To optimize the responses by people with intellectual disabilities, the starting point was that caregivers allowed the person with intellectual disabilities to speak for themselves as much as possible. Caregivers could support the person with intellectual disabilities by offering reminders; this was helpful.

Implications for research and practice

This study explored the role of the specialized medical ID expertise of ID physicians in the Netherlands. Adopting an international perspective to explore the roles of other medical professionals specialized in people with intellectual disabilities could provide more insight into what works in various contexts. Several calls have been made to better equip medical professionals for patients with intellectual disabilities by including knowledge about this patient group in medical curricula [2, 44-46]. Our study provides insight into the diversity of content that can be included in curricula and training programmes, such as advocacy and collaboration themes in addition to clinical and relational themes. The CanMEDS framework provides tips for teaching and assessing health advocacy and collations [38]. Furthermore, involving people with intellectual disabilities and their caregivers in the development and/or delivery of medical training programmes can facilitate more positive attitudes and improves students' skills and confidence when working with people with intellectual disabilities [47]. Future studies could explore which of the roles identified in our study need to be addressed by medical professionals specialized in ID and which roles could be addressed by mainstream medical care providers. Lastly, the roles identified in our study are relevant for other vulnerable populations with complex care needs, such as patients with dementia or low health literacy.

Conclusion

By shifting the focus from the extensively documented barriers to medical care for people with intellectual disabilities to highlighting desirable roles, actions, and attributes for medical care professionals, this study provides an alternative approach to understanding the valuable elements of medical care for patients with intellectual disabilities. Patients with intellectual disabilities and their caregivers value ID physicians' roles beyond their clinical skills during consultations, including roles related to the coordination of care, having a professional network, and being an advocate in a broader context around medical consultations. This diversity in roles can be included in curricula for current and future medical care professionals.

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Appendix

Supplementary File S5.1 Easy-to-read information letter in Dutch

De zorg van de arts voor mensen met een verstandelijke beperking

Je ontvangt deze brief omdat je de arts voor mensen met een verstandelijke beperking (afgekort: arts VG) in Nijmegen hebt bezocht.
Je kunt iemand om hulp vragen om samen de brief te lezen.

Hoi, ik ben Marian.

Ik doe onderzoek naar de zorg van de arts VG.

Wil je meedoen aan mijn onderzoek?

Deze brief helpt je om te kiezen.

Waar gaat dit onderzoek over?

Het onderzoek gaat over de zorg van de arts VG in Nijmegen.
Dit is een dokter die mensen met een verstandelijke beperking goed kan helpen.

Dit is wat ik wil weten:
Ik wil graag van jou horen hoe jij de zorg van de arts VG vond.
Vond je dat de arts VG je goed kon helpen en waarom?

Waarom ik dit wil weten:
De zorg van de arts VG in Nijmegen is nieuw.
Door te kijken naar wat jij van de zorg vindt, kunnen we de zorg beter maken.

Wat gaan we doen?

We doen een interview. Dat is een gesprek met Marian.
Zij stelt vragen en luistert naar jouw antwoorden.
Het gaat om wat jij vindt. Als je iets niet wilt vertellen, dan hoeft dat niet.
Het gesprek duurt ongeveer 1 uur.

Het gesprek wordt opgenomen zodat we goed kunnen terug luisteren wat er is gezegd.
Als het onderzoek klaar is schrijven we een verslag.
Jouw naam staat niet in het verslag.

Doe je mee met het onderzoek?

Als je mee wil doen, help je ons.
Zo weten we wat jij van de zorg van de arts VG vindt.
Met die informatie kunnen we de zorg beter maken.

Meedoen heeft geen voordeel voor jou.
Het kost je alleen tijd.
Je mag zelf kiezen of je meedoet.

Wat zijn de afspraken als je meedoet?

Als je mee wilt doen, dan zet je je handtekening op een toestemmingsformulier.
Dit formulier heb je ook gekregen.
Als je een vraag hebt, mag je Marian mailen.
Na het onderzoek mag je de informatie die we over jou opslaan, opvragen als dat nodig is

Bedankt voor het lezen en misschien tot snel!

Heb je vragen?
Mail naar: Marian.Breuer@radboudumc.nl

STERKER
OP EIGEN BENEN

Supplementary File S5.2 Easy-to-read informed consent form in Dutch

TOESTEMMINGSFORMULIER

Dit formulier vul je in als je mee wilt doen aan het onderzoek.
Je kunt iemand om hulp vragen om samen met je de tekst te lezen en je handtekening te zetten.

Ik heb de informatiebrief over het onderzoek gelezen.
Ik heb de onderzoeker vragen kunnen stellen.
Mijn vragen zijn beantwoord.
Ik heb genoeg tijd gehad om erover na te denken of ik mee wil doen.

Ik geef toestemming voor het afnemen van een interview.
En voor het opnemen van dit interview.
Ik weet dat meedoen vrijwillig is.
En dat ik op ieder moment kan stoppen zonder dat ik hoef te vertellen waarom.

Ik weet dat mijn gegevens vertrouwelijk worden behandeld.
Ik weet dat de onderzoekers mijn gegevens kunnen inzien zoals dat in de informatiebrief staat.
Ik geef toestemming om de informatie over mij nog 10 jaar na afloop van dit onderzoek te bewaren.

Datum:
Naam deelnemer:

Handtekening deelnemer:

Datum:
Naam onderzoeker:

Handtekening onderzoeker:

STERKER
OP EIGEN BENEN

Chapter 6

General discussion

General Discussion

This thesis has explored the role of specialized expertise in the medical care for people with intellectual disabilities (ID) to identify opportunities to improve this care both internationally and in the Netherlands. Although the context of medical care, including the way specialized medical ID expertise is embedded in healthcare, differs internationally, we identified universal healthcare challenges (Chapter 2 & 3). We found that specialized medical ID expertise is of value in assessing medical, psychological, and context-related health problems in interaction with each other and in the broader context of a patient's everyday life (Chapters 4 and 5). Besides this clinical value, specialized medical ID expertise was found to be of value in navigating the complex organizational arrangements in the healthcare for people with ID, by including the patient's social context as well as by coordinating healthcare for people with ID (Chapter 5).

Combining all insights, we conclude that embedding specialized medical ID expertise in healthcare systems can contribute to improved medical care for people with ID. This requires comprehensive consideration of 1) the *context* in which medical care provision takes place, 2) the *content* of the actual medical care consultations, and 3) the *perspectives* on prerequisites and experiences of medical care as recounted by researchers, healthcare professionals, patients with ID, and their support persons. Below, these three aspects and their implications for research, policy, education, and practice are discussed.

Context

The Dahlgren-Whitehead model of the main determinants of health illustrates that health outcomes are influenced by determinants on multiple interconnected layers (Figure 6.1) [1]. The three outer layers of this model reflect the context surrounding a person. Successfully improving the health of people with ID requires determinants on all layers to be addressed in interaction with one another. Focusing solely on one aspect without considering the others may result in incomplete or contextually inappropriate interventions. For example, focusing merely on improving the content of healthcare services by educating medical professionals about people with ID without considering the unique context in which this education can be implemented may prove to be ineffective. Chapters 2 and 3 focus on the fourth and outer layer of the Dahlgren-Whitehead model, by exploring the role of context on the level of international organization of healthcare for people with ID. Chapters 4 and 5 focus on the second and third layer, exploring the role of the patient's context during medical consultations.

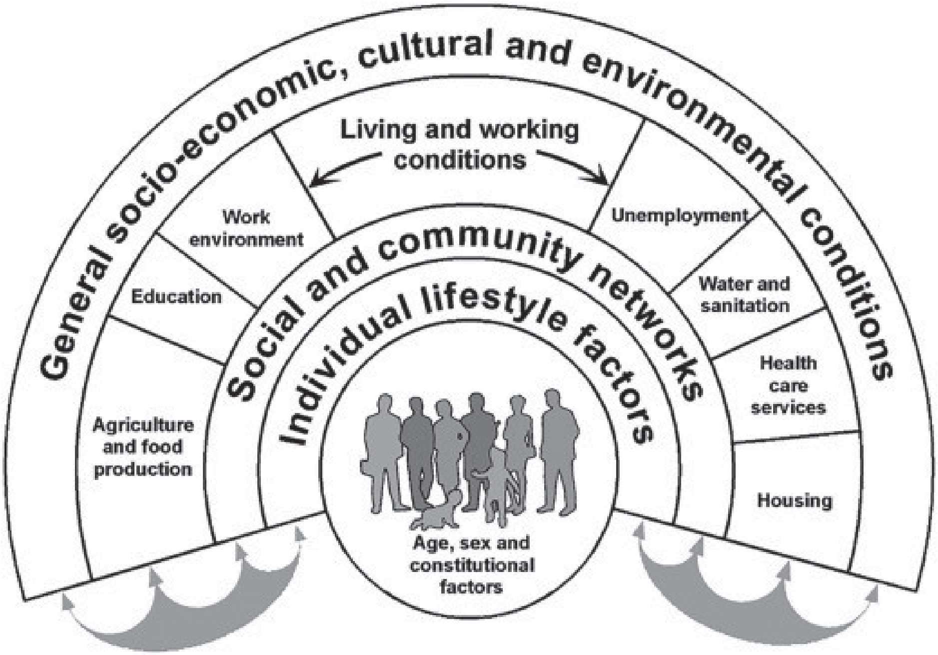

Figure 6.1 The Dahlgren-Whitehead model of health determinants

The role of the international context

Despite international differences in the organizational context of healthcare for people with ID, this thesis shows that countries face similar challenges (Chapters 2 and 3). Two of the challenges identified in Chapter 3, access to and quality of healthcare, are acknowledged in Article 25 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) [2]. This thesis adds two universal challenges which deserve attention in international cooperation towards equitable healthcare for people with ID as well. First, the implementation of policies into action remains suboptimal, leading to inadequate quality of healthcare for people with ID. Second, there is a lack of data on the ID population, which makes it more difficult to understand and respond to the health needs of people with ID. International collaboration creates learning opportunities and critical reflection on current practices, which can boost efforts in research, healthcare development, and healthcare delivery, as well as training and education for healthcare professionals. The opportunities for international collaboration to improve the healthcare for people with ID are currently not used to their full potential. For instance, the European Observatory on Health Systems gathers and compares information on health systems in general and internationally to give decision makers insights into how their systems operate [3]. Such networks do not yet exist for ID healthcare.

Chapter 3 of this thesis synthesizes best practices in the healthcare for people with ID around the world. Identification of these best practices provides the opportunity to learn from the successes and positive results of other countries. However, successful translation of best practices is not straightforward and needs careful consideration [4]. Innovations are often developed and tested on efficacy within a specific setting or care organization, overlooking the influence of context on their effect. Factors such as severity of the ID, available resources, socioeconomic conditions, and cultural considerations all contribute to the shaping of the context in which these innovations are implemented. Before best practices are translated across countries, assessing how these align with the implementation context requires a deep understanding of this specific context [4]. Examining the role of context in transferring effective practices is especially important in the context of medical care for people with ID, given the diversity of this population and the different settings in which medical care provision takes place.

The role of context during individual medical consultations

The patient's context plays a role during individual medical consultations in two ways: 1) by assessing the health problems of patients with ID within the patient's context (i.e., the third layer of the Dahlgren-Whitehead model), and 2) by including the social context, that is the support person, of patients with ID during medical consultations (i.e., the second layer of the Dahlgren-Whitehead model).

First, Chapter 4 shows that people with ID often experience multiple and multifaceted health problems at the same time, and that the patient's history and context, in which ID is an underlying factor, play a major role in adequately assessing these health problems. This includes taking into account the way ID can influence all levels (medical, psychological, contextual) of the experienced health issue within the context of everyday life. This is important, because ID, related co-morbidities, and the patient's context can influence the expression of symptoms, which can complicate the diagnostic process and treatment of various other medical and psychological problems. These problems might go unnoticed if the focus is on just the ID or on a specific medical or behavioural problem, risking over-, under- or misdiagnosis and -treatment [5]. In Chapter 5, respondents perceived a holistic view as an important role for specialized ID physicians with regard to providing adequate healthcare. The example of a patient referred to a specialized ID physician by the GP for behavioural problems in Chapter 4 illustrates this. The ID physician found that the patient's behavioural problems could be explained by hearing difficulties, which caused him to miscomprehend his environment, resulting in angry behaviour. Overlooking the patient's context in the assessment might have caused the patient's behavioural problems to be treated incorrectly. Therefore, medical professionals who encounter people with ID should be aware of the influence of the patients' context on their health complaints.

Second, people with ID are often dependent on their support persons (e.g., parents or daily care professionals) to access medical care [6]. Including the support persons of people with ID during medical consultations helps to create a better understanding of the patient's context, both for assessing the health complaints and for developing an attainable treatment plan within the patient's context (Chapter 5). Support persons can for instance help articulating the patient's complaints and they have a broader understanding of the patient's context than the medical professional. Chapter 5 shows that collecting information about the patient's context from the patient as well as from the support persons is an important role of medical professionals who encounter people with ID.

Thus, acknowledging the relevance of the patient's context during individual medical consultations lowers the risk for over-, under- or mistreatment. The influence of the patient's context is seen in other patient groups who encounter complex medical situations as well, for example in geriatrics. Currently, linear cause and effect reasoning, in which the patient's context is underacknowledged, forms the basis of much of the problem solving in clinical encounters [7]. In geriatrics and general practice, models that are better able to accommodate this complexity in medical care provision are being explored [8, 9]. This complexity approach helps to better tailor medical care to individual patients and their complex health problems [8].

Content

This thesis elucidates that the content of medical care for people with ID goes beyond the clinical care provision between professionals and patients. Themes such as active patient involvement, medical care professionals' expertise, complexity of performing diagnostics, and communication are internationally mentioned as important characteristics in the medical care for people with ID (Chapter 2). This thesis reflects on two aspects of the content of medical care for people with ID: 1) the role of specialized expertise in the medical care for people with ID and 2) the content of medical training about people with ID.

The role of specialized medical ID expertise

Chapters 4 and 5 of this thesis focus on patients with ID for whom specialized medical ID expertise was requested by GPs and elucidate the role of this expertise in the medical care for people with ID in two ways. First, by identifying where professionals with specialized medical ID expertise can support mainstream medical care professionals (Chapter 4). Second, by exploring the roles of specialized ID physicians according to patients' experiences (Chapter 5).

Chapter 4 shows that GPs often refer to specialized ID physicians in the case of psychological problems, which frequently concerned behavioural problems, suggesting that GPs encounter challenges in assessing these problems in people with ID. We found that GPs' reasons for referring to specialized ID physicians are often more generic than the problems identified by ID physicians during consultations. Patients were also referred without specification of a reason, besides the patient having an ID. This implies that GPs often suspect that ID play a role in patients' health complaints, but do not know in what manner. The complex, multifaceted nature of health-related problems of people with ID requires a high level of expertise regarding these patients' morbidity patterns in their different stages of life (Chapter 4). Despite the broad focus on medical, psychological, and context-related issues, GPs have acknowledged to experience challenges in treating patients with ID [10, 11]. Because of their expertise, ID physicians can assess health complaints in an integrated way, taking into account the influence of ID on physical problems, psychological problems, and problems in the context of everyday care and living. This is important, because ID or related co-morbidities can influence the expression of symptoms, complicating the diagnostic process and treatment of various other physical and psychological problems that might go unnoticed if the focus is either on ID or on a specific medical or behavioural problem, risking over-, under- or mistreatment [5]. In addition, physicians without specialized ID expertise may not recognize the presence of ID in their patients since it is often not registered if a patient has an ID [12, 13]. This also increases the risk of misdiagnosing their complaints and applying diagnostic processes and treatments that are not tailored to the patient with ID [12].

This thesis shows that the content of medical care for people with ID goes beyond the clinical care provision between professionals and patients. In Chapter 5, respondents mentioned roles of ID physicians that reflect clinical, relational, and contextual competences. ID physicians are trained in applying the core themes of person-centred care, such as relational aspects, communication, and coordinated care [14]. Furthermore, they are aware of additional themes relevant in the medical care provision for people with ID, such as including the support network of people with ID in their medical care provision, knowing when to deviate from clinical guidelines, if substantiated, and advocating for the rights of people with ID (Chapter 5). This way, ID physicians have different roles in the medical care for people with ID (Chapter 5).

In recent years, the interpretation of the role of ID physicians has broadened, increasing the demand for specialized medical ID care in the Netherlands. The growth in the number of ID physicians cannot keep up with this growing demand. Shortages in the number of ID physicians in the Netherlands have caused limitations in the provision of specialized medical ID care [15-17]. Therefore, optimal medical care for people with ID requires careful collaboration and coordination between GPs, ID physicians, and other involved professionals so that each expertise can be used most effectively [18, 19]. Not all care demands require specialized expertise or even a medical approach. ID physicians can support mainstream medical care professionals in understanding the role of ID in complex health problems. Several residential care organizations for people with ID have restructured their care into the so-called stepped care model, in which health problems of people with ID are first seen by nurse specialists, before GPs or ID physicians are engaged. In this model, GPs and ID physicians only receive those care questions that require their expertise [20]. By providing insight in the care questions that GPs find challenging, this thesis facilitates shaping the stepped-care model for people with ID. The precise implementation of the stepped-care concept varies greatly between organizations and involves customisation based on for example the size of the organization, the care content, and the number and type of care professionals employed [20].

Agreements about who is responsible in which situations and mutual exchange of information are essential for successful collaboration [19]. To facilitate collaboration between GPs and ID physicians, the National General Practitioners Association of the Netherlands has provided a guideline with a model agreement [19]. However, individual responsibilities remain unclear, and further agreements on preconditions and facilitations of medical care have been made [21]. Including the patient's support person, who can play an important supporting role for both the patient and the physician in medical care (Chapter 3), could be a valuable addition to the current agreements. The upcoming roles of ID nurse specialists, physician assistants, or (practice) nurses in the medical care for people with ID are another promising development, highlighting possibilities for task relocation.

Content of medical training about people with ID

Chapters 2 and 3 show that training medical care professionals regarding the health of people with ID is internationally seen as an important prerequisite for improved medical care for this population. Although several calls have been made to include knowledge about people with ID in medical curricula [22-25], medical professionals report a need for additional education and a lack of knowledge regarding ID [10, 11]. In many countries, exposure to ID during training is limited because of the little time available for training and this contributes to an increase in the stigma that these people already face [26].

In addition to these practical constraints, there is no consensus on the form that the medical training about people with ID should take. Various training modalities are used around the world, with a debate about whether there should be a subspecialty in ID (specialization) or whether all medical professionals should undergo ID training (mainstreaming) [27, 28]. Specialization has been criticized for increasing segregation of care, resulting in lack of integration with mainstream medical practices and potentially hindering comprehensive and coordinated care for people with ID [27]. In contrast, mainstreaming has been shown to be difficult to implement because it requires coordination, resources, and a commitment from medical schools [27].

People with ID encounter many different healthcare professionals in their life, making it imperative that mainstream professionals are equipped with some basic tools and skills to provide effective and compassionate care for this population. Integrating comprehensive modules on the health and medical care needs of people with ID into medical school curricula increases future healthcare professionals' confidence, competence, and attitudes towards people with ID [29, 30]. For current healthcare professionals, the opportunity to enhance their skills and understanding of the health and medical care needs of people with ID could be provided through post-graduate vocational training.

Awareness that ID can cause different presentations of health problems, that people with ID have complex medical care needs, and that the expertise of specially trained medical care professional is available would help both patients with ID and healthcare professionals. Furthermore, it would be helpful to pay attention to teaching about how to assess the combination of medical, psychological, and context-related problems and their possible interaction with ID (Chapter 4). The CanMEDS (Canadian Medical Education Directives for Specialists) competency framework [31] used in the development of medical training programmes offers several opportunities for including themes on people with ID. For instance, the collaborator and health advocate roles included in this framework are significant in the medical care for people with ID (Chapter 5). In practice however, many medical curricula focus on the medical expert and communicator roles [20, 21]. Medical training that involves people with ID in the development and/or delivery of the teaching fosters positive attitudes and improves students' skills and confidence when working with people with ID [29, 32]. In short, specialization and mainstreaming are both necessary to optimize care for people with ID.

Perspectives

There is a wide variety of perspectives on the medical care for people with ID which need to be involved when improving this care. This thesis explored what international professionals and researchers understand by medical care for people with ID (Chapter 2). We found different interpretations of this concept. Furthermore, this thesis explored patients' and their support persons' perspective on medical care (Chapter 5). This provides guidance for steps towards person-centred medical care for people with ID.

Different perspectives regarding medical care for people with ID

The international studies in this thesis (Chapters 2 and 3) highlight that it is not a given that people have the same understandings of concepts related to the medical care for people with ID. In Chapter 2, researchers and practitioners completed the prompt "If you asked me to describe medical care for people with ID in my country, I would say…" with a wide variety of statements, reflecting descriptions of current medical practice, ideas on good medical practice, and aspirations for future medical care. These perspectives need to be involved in improving healthcare, because, to take effect, changes need to be truly relevant to the situation as well as meaningful to those involved [33]. International learning and collaboration are hampered by the different understandings of medical care for people with ID.

Chapter 3 showed a lack of shared and uniform conceptualizations and definitions of concepts such as residential care facility and IDD/ID. For instance, in the United States, people with ID live in residential care facilities when they have a treatment indication, whereas, in other countries, people with ID more commonly live in these facilities either with or without a treatment indication [34, 35]. These organizational differences lead to variation in interpretations of concepts. The terms ID and IDD are often used interchangeably; in some cases, the term IDD is understood as referring to individuals with intellectual disability who have additional developmental disabilities, and, in other cases, the term is understood as referring collectively to individuals with intellectual disability and individuals with other developmental disabilities who do not have intellectual disability, for example people with dyslexia. The growing use of the term IDD in the absence of an agreed definition can cause difficulties, for example for estimating prevalence figures. To ensure the success and comparability of research efforts across borders, it is essential that we prioritize the development of uniform definitions for IDD/ID. Until this common language is found, it is imperative that interpretations and understandings of fundamental concepts are clearly described in research and policy documents.

Towards person-centred care for people with ID

Chapter 5 shifts the focus from the extensively documented barriers in medical care for people with ID to patients' perspectives on desirable roles, actions, and attributes for medical care professionals. These findings specify the needs of people with ID regarding their medical care professionals, offering guidance for steps towards person-centred care.

In healthcare, a growing emphasis is placed on person-centred care, which prioritizes the needs and preferences of individuals receiving healthcare services [14, 36]. Important themes in person-centred care include care professionals' relational characteristics, communication, shared decision making, both a holistic and an individualized focus, and coordinated care [14]. In the general population, person-centred care has been found to have positive effects on health(care) outcomes, including increased patient involvement; higher satisfacton of patients, informal carers, and healthcare professionals; higher treatment concordance; fewer referrals and follow-up examination; improved self-management skills; and fewer emergency department visits and hospital (re)admissions [37, 38]. Consequently, person-centred care is viewed as a core value in providing high-quality healthcare and essential to achieving the universal health coverage goals of the World Health Organization [39].

Person-centred care is particularly important for vulnerable populations, including people with ID, because of the recognition and respect for their unique and diverse needs, preferences, and abilities [37]. Research on person-centred care in vulnerable populations, including people with ID, is underrepresented, although some positive effects of person-centred care have been identified in the care for people with ID, such as better well-being, care satisfaction, and job satisfaction among professionals and informal caregivers [40, 41].

This thesis has identified themes to consider in working towards person-centred medical care for people with ID. These themes are reflected in the perspectives of experts, patients, and their support persons and include the active patient involvement (Chapters 2 and 5), the professionals' expertise (Chapters 2, 4, and 5), the role of support persons (Chapter 5), and advocacy (Chapter 5). Patient involvement in medical care and decision making is generally seen as essential, but, for patients with ID, this can be more complicated because of communication challenges [42]. Chapter 5 shows that the ID physician's skills help to overcome challenges in regular medical care in this regard. In addition, physicians who encounter people with ID have to make informed decisions about deviating from guidelines, if substantiated, to tailor medical care to patients' needs (Chapter 5). Furthermore, Chapter 5 states that to work towards person-centred care for people with ID, their support persons have to be included, as they play an important supporting role for both patient and professional during medical care. Medical professionals' advocacy role is strong in the medical care for people with ID (Chapter 5), because having ID can make self-advocacy difficult [31]. Some of these themes also seem to be relevant for other vulnerable populations with complex care needs, such as patients with dementia [43]. In working towards person-centred care for vulnerable populations, these themes can be further explored.

Methodological considerations

The medical care for people with ID is complex and involves many different stakeholders from different backgrounds. A wide range of stakeholders were involved as study participants throughout this thesis: researchers, healthcare professionals, patients with ID, and their support persons. To provide a rich understanding of the different aspects of medical care, this thesis has applied both qualitative and quantitative methods.

The international studies of this thesis were complicated by lack of clarity about definitions of certain fundamental concepts (e.g., residential care facility, IDD/ID, and medical care). Efforts were made to mitigate this limitation through repeatedly discussing different interpretations with researchers from different countries in online meetings and by providing a template that could be applied to all participating countries. Despite these efforts, the inherent complexity of these concepts remains a present limitation, because some collected data (e.g., prevalence figures) may not be fully comparable across countries.

The research described in this thesis took place during the COVID-19 pandemic, which caused challenges related to engaging with international researchers. The international congresses, which were to be visited to connect with international researchers for the purpose of this thesis, were cancelled. Therefore, data collection for the international studies was performed online, which is an efficient way of collecting data from participants who are geographically disparate as it enables participants to engage in the project from their own desks. To further address the constraints related to the pandemic, the online platform HealthIDea (www.HealthIDea.nl) was developed as part of this thesis project. HealthIDea aims to stimulate and facilitate the exchange of knowledge and experience between experts regarding the health of people with ID. In response to a project hosted on HealthIDea, the idea arose to initiate a special edition on the international organization of healthcare for people with ID. This idea was reinforced by the different international responses to the COVID-19 pandemic for people with ID, which stressed that understanding the context in which healthcare is provided is important to learn from other countries and improve healthcare. This thesis synthesizes the 13 special edition papers in Chapter 3. Another COVID-related challenge concerned obtaining informed consent from patients visiting the outpatient ID practice. We decided to work with active (opt-in) informed consent rather than opt-out. This required all patients to respond to an informed consent form. However, during the first year of the pandemic, care for people with ID was often focussed on staying healthy and adhering to all measures. Reading and sending back informed consent forms was hindered by this (Chapter 3).

Investigating the Dutch setting in Chapters 4 and 5 provided a unique opportunity to explore the role of specialized medical ID expertise and patients' experiences with specialized ID physicians. The patient-specific medical needs and preferences presented in Chapter 5 might translate to patients with ID in other settings, because, regardless of the organizational context of the healthcare system, patients with ID may have similar needs and preferences in medical care. In contrast, the findings of Chapter 4 might be less generalizable to other settings because the health problems of people with ID found in outpatient ID practices (e.g., long-term health problems) may differ from other settings such as for example hospitals (e.g., acute health problems).

Only persons with mild to moderate ID, who were able to communicate verbally, could participate in the study in Chapter 5. With help from the co-researchers, data collection methods were adjusted to enable them to participate. To also include the voice of people with profound or severe ID, proxy respondents were sought. Proxy answers may not accurately represent the true thoughts or intentions of the individual they are standing in for [44]. The combined answers of people with ID and their support persons resulted in a richer perspective than would have been obtained by including only patients or only support persons. To optimize the responses by people with ID, the starting point was that support persons allowed the person with ID to speak for themselves as much as possible. Support persons could support the person with ID by offering reminders; this proved helpful.

Conclusion

This thesis identified opportunities to improve the medical care for people with ID, while acknowledging the international differences in the organizational structures of this care. Improving medical care to meet the needs of people with ID requires a comprehensive consideration of context, content, and perspectives. These elements are interconnected, and successfully embedding specialized medical ID expertise in healthcare systems requires them to be addressed in interaction with one another. The recommendations emanating from this thesis are summarized in Box 6.1.

Box 6.1 Summary of recommendations

Research

- Facilitate international ID healthcare research, for example by using online platforms or databases where international researchers can share information, resources, and data related to ID health and healthcare research (e.g., www.HealthIDea.nl)
- Appreciate complexity in the medical care for people with ID
- Further investigate aspects of medical care for people with ID beyond the practical medical care provision between providers and patients
- Determine in which situations referral to specialized services is especially helpful
- Clearly describe interpretations and understandings of fundamental concepts used in research (e.g., residential care facility, IDD/ID, and medical care) and describe the context in which research is performed
- Explore when, why, and how person-centred care leads to positive results in people with ID

Policy

- Encourage and fund research initiatives that focus on improving medical care and health outcomes for people with ID
- Raise awareness of the value of specialized medical ID expertise
- Provide clear guidelines about who is responsible for what medical care questions for people with ID and include the patient's support person in these guidelines
- Use feedback from people with ID, their families, and other stakeholders to continually refine and enhance the delivery of medical care

Education

- Integrate comprehensive modules on the health and medical care needs of people with ID into medical school curricula, including the combination of medical, psychological, and context-related problems and the possible interaction with ID
- Involve people with ID in the development and/or delivery of the programme
- Develop post-graduate vocational training on (the health of) people with ID for current healthcare professionals
- These educational programmes should go beyond teaching clinical skills and include relational and contextual competence, for instance following the CanMEDS roles

Practice

- Assess the complex and multifaceted medical complaints of patients with ID in patients' context and be aware of the influence of ID or related co-morbidities
- Involve the support persons of people with ID in medical care, both in diagnostics and in developing an attainable treatment plan within the context
- Be aware of the possibility to refer to a specialized medical professional (e.g., ID physician) when available for support in understanding the role of ID in complex health problems and coordinating a multidisciplinary approach

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Chapter 7

Summaries

English summary

It is estimated that people with intellectual disabilities (ID) comprise approximately 1-3% of the global population. People with ID have different medical care needs compared to the general population. They may experience difficulties in recognizing and expressing signs of disease, present symptoms in an atypical way, may experience communication difficulties, have different morbidity patterns than the general population, and experience more comorbidity and syndrome-related disorders. Medical care providers do not always feel equipped to manage these ID-specific needs. Consequently, people with ID are often misunderstood and their illnesses mis- or undiagnosed, leading to a greater burden of multi-morbidity, higher levels of undetected and inadequately managed health problems, health inequalities, and higher rates of avoidable deaths.

Several calls to include knowledge about people with ID in medical curricula in order to improve medical care for this population have been made. However, there is no consensus on what specialized medical training about people with ID should look like. There is need for more knowledge on the role of specialized ID expertise in the medical care for people with ID.

Countries have developed diverse approaches to provide their medical care. Consequently, the organization of medical care, and the role of specialized medical ID expertise, differs internationally. These differences allow for international learning, but international collaboration is hampered by the lack of an international overview of the organization of medical care for people with ID. The Netherlands provides a unique situation to investigate this, because of the acknowledgement of an ID physician specialized in providing medical care for people with ID. ID physicians are trained during a three-year postgraduate course in all the aspects of specialized medical care for people with ID.

The overall aim of this thesis is investigating the role of specialized ID expertise within the medical care for people with ID and identifying opportunities to improve (the organization of) this care. To reach this aim, this thesis provides insight in the international context and perspectives on medical care for people with ID and the Dutch content of and perspectives on (specialized) medical care for people with ID.

Chapter 2 aims to explore how international experts on medical care for people with ID (researchers and practitioners) describe this care. Twenty-five experts from 17 countries submitted statements on medical care in their country in a brainstorming session. Next, they sorted all collected statements and rated them on importance. Based on the sorting of all statements, a concept map was formed, covering 13 aspects that characterize medical care for people with ID across nations. The 13 aspects varied minimally in importance ratings and were grouped into five overarching conceptual themes: (i) active patient role, (ii) provider role, (iii) context of care, (iv) consequences of care for people with ID, and (v) quality of care. These themes show that the medical care for people with ID is described as encompassing more than only the practical medical care provision between providers and patients.

A special edition on the organization of healthcare for people with ID in 13 countries was initiated as part of this thesis. **Chapter 3** explores the similarities and differences in the international context of healthcare for people with ID by synthesizing the 13 special edition papers. We found that, despite differences in context, countries face similar challenges in improving healthcare for people with ID. These challenges cover: 1) access to healthcare, 2) quality of healthcare, 3) implementation, and 4) visibility of people with ID. Several best practices have been developed, ranging from making mainstream healthcare more accessible and suitable to providing specialized services, and advocating and raising awareness.

Chapter 4 explores the Dutch content of medical care or people with ID. Characteristics of specialized medical care for people with ID, including the interplay between medical, psychological, and context-related problems were described. Medical records (n=128) of patients with ID who had visited the outpatient ID practice in Nijmegen, the Netherlands were analysed, focusing on 1) reasons for initial consultation, 2) health-related problems identified during initial consultation, and 3) disciplines involved following initial consultation. While patients were often referred to the outpatient ID practice for one type of complaint, diverse, multiple, and interconnected problems were frequently identified during specialized medical ID consultations. After initial consultation, a range of other specialist professionals (n=25) were involved by the ID physician, indicating a need for multidisciplinary approaches in the healthcare of people with ID.

Chapter 5 explores patients' and their support persons' experiences with and expectations of a medical consultation with a specialized ID physician at an outpatient ID practice. Fifteen patients of the outpatient ID practice in Nijmegen, the Netherlands, and their support persons were interviewed. They reflected on their experiences with and expectations of ID physicians, focusing on 1) knowledge and skills of ID physician, 2) communication between participants and ID physician, and 3) coordination between ID physician and other care providers. Analysis resulted in seven themes addressing roles of the ID physician. Five roles relate to actions and attributes of the ID physician during medical consultations: clinician, patient-centred doctor, holistic physician, human, and sparring partner for the patient's network. Two roles relate to actions and attributes of the ID physician around medical consultations: coordinator and advocate.

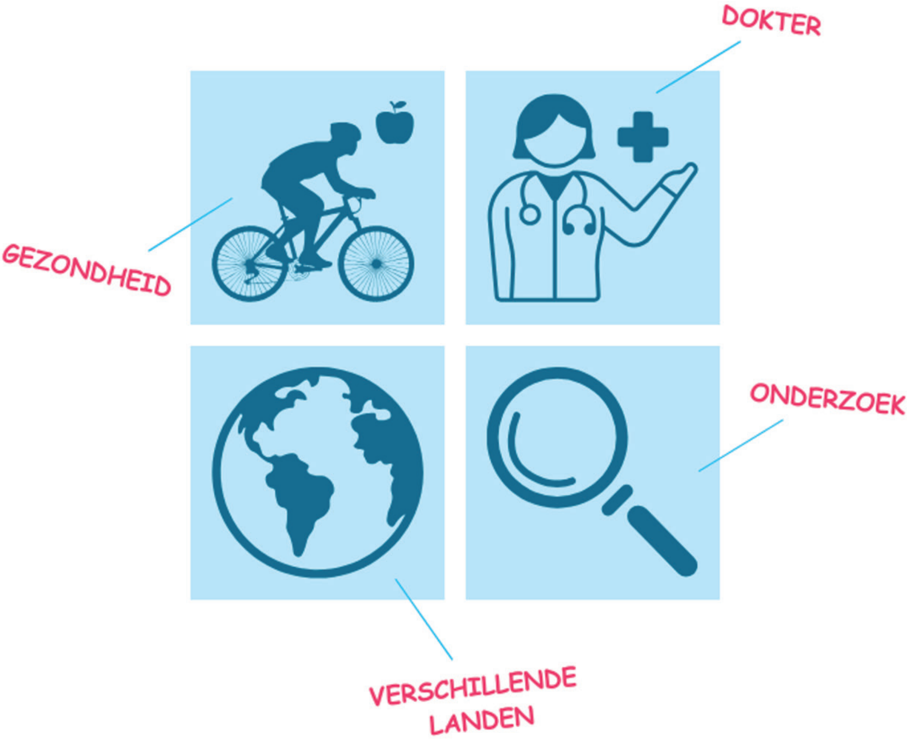
The final chapter, **Chapter 6**, reflects on the main findings of this thesis and concludes that embedding specialized medical ID expertise in healthcare systems contributes to improved medical care for people with ID. This requires comprehensive consideration of 1) the context in which medical care provision takes place, 2) the content of the actual consultations, and 3) the perspectives on prerequisites and experiences of medical care by researchers, healthcare providers, patients with ID, and their support persons. These elements are interconnected and successfully embedding specialized medical ID expertise in healthcare systems requires addressing them in interaction with each other. Focusing solely on one aspect without considering the others may result in incomplete or contextually inappropriate interventions.

Nederlandse samenvatting

Mensen met verstandelijke beperkingen (VB) hebben specifieke medische zorg nodig. Omdat dokters soms niet weten hoe ze deze zorg moeten geven, worden gezondheidsproblemen bij deze mensen vaak niet goed gezien en behandeld. In Nederland leren speciale dokters (artsen voor verstandelijk gehandicapten; afgekort artsen VG) hoe ze goede zorg kunnen geven aan mensen met VB. Artsen VG hebben gespecialiseerde kennis over mensen met VB en hun gezondheidsproblemen. Dit proefschrift verkent wat de rol is van deze gespecialiseerde kennis in het verbeteren van de zorg voor mensen met VB. In **Hoofdstuk 2** kijken we hoe dokters en onderzoekers uit 17 landen de medische zorg voor mensen met VB beschrijven. We vonden 5 belangrijke onderwerpen over deze zorg: 1) de patiënt, 2) de dokter, 3) de omgeving, 4) de gevolgen van zorg en 5) de kwaliteit van zorg. In **Hoofdstuk 3** vonden we dat de zorg in elk land anders geregeld is. Toch staan landen voor dezelfde uitdagingen om de zorg te verbeteren. Deze uitdagingen gaan over: 1) toegang tot zorg, 2) kwaliteit van zorg, 3) implementatie en 4) zichtbaarheid van mensen met VB. In sommige landen zijn er goede manieren (ook wel 'best practices' genoemd) gevonden om de zorg te verbeteren. **Hoofdstuk 4** gaat over de zorg die de arts VG geeft op de AVG (Arts Verstandelijk Gehandicapten) praktijk in Nijmegen. Veel huisartsen verwijzen patiënten naar de AVG praktijk met psychologische klachten. De problemen van deze patiënten zijn ingewikkeld, omdat er vaak meerdere gezondheidsproblemen in één patiënt worden gevonden en omdat er vaak problemen op meerdere vlakken gevonden worden, bijvoorbeeld in het lichaam, in het hoofd, of in de omgeving van de patiënt. Er werden veel verschillende dokters betrokken om de gezondheidsproblemen van de patiënten te behandelen. **Hoofdstuk 5** gaat over wat patiënten en hun ouders belangrijk vinden in hun arts VG. Ze noemden zeven thema's die ze belangrijk vonden: 1) goede medische zorg geven, 2) de patiënt mee laten doen, 3) niet alleen kijken naar het lichaam, maar ook naar de omgeving van de patiënt, 4) vriendelijk zijn, 5) overleggen met de ouders van de patiënt, 6) de zorg regelen en 7) opkomen voor mensen met VB. In **Hoofdstuk 6** voegen we alle uitkomsten van ons onderzoek samen en concluderen we dat gespecialiseerde medische kennis over mensen met VB bijdraagt aan het verbeteren van hun medische zorg. We moeten daarbij drie dingen meenemen: 1) hoe de zorg geregeld is, 2) hoe de zorg gegeven wordt en 3) wat mensen vinden van de zorg.

Makkelijk lezen samenvatting

Een onderzoek over de medische zorg voor mensen met een verstandelijke beperking



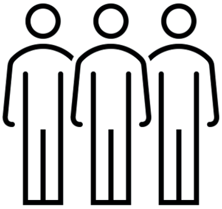
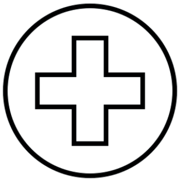
Hoofdstuk 1

Inleiding

Wat staat er in deze inleiding?

	In deze inleiding staat een onderzoek opgeschreven. Het onderzoek gaat over de medische zorg voor mensen met een verstandelijke bepekring. De medische zorg is de zorg van de dokter. Bijvoorbeeld de huisarts of de arts voor verstandelijk gehandicapten.

Waarom is dit onderzoek belangrijk?

	Mensen met een verstandelijke beperking hebben soms andere dingen nodig dan andere mensen. Dat is ook zo in hun medische zorg. Bijvoorbeeld extra hulp in communicatie. De dokter kan niet altijd extra hulp geven.
	Het is belangrijk om te weten hoe de medische zorg eruitziet. Als we dat weten, kunnen we de zorg verbeteren.

Wat waren de doelen van het onderzoek?

?	De vraag van dit onderzoek was: Hoe ziet medische zorg voor mensen met een verstandelijke beperking eruit?
③	We keken naar: 1. Hoe de zorg geregeld is 2. Hoe de zorg gegeven wordt 3. Wat mensen vinden van de zorg

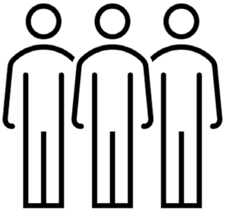
Hoofdstuk 2

Hoe omschrijven mensen uit verschillende landen de medische zorg voor mensen met een verstandelijke beperking?

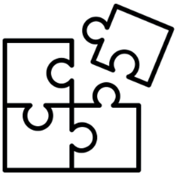
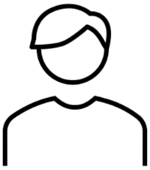
Wat wilden we weten?

	Dit onderzoek gaat over de medische zorg voor mensen met een verstandelijke beperking. De medische zorg is de zorg van de dokter. Bijvoorbeeld de huisarts of de arts voor verstandelijk gehandicapten.
	De vraag van dit onderzoek was: Hoe omschrijven mensen de medische zorg voor mensen met een verstandelijke beperking?

Wat hebben we gedaan?

	Dokters en onderzoekers uit 17 landen deden mee met: 1. Ideeën verzamelen 2. Ideeën sorteren

Wat zijn we te weten gekomen?

	We vonden 4 onderwerpen: 1. De patiënt 2. De dokter 3. De omgeving 4. De gevolgen van de zorg
	**1. De patiënt** Onderwerpen die met de patiënt te maken hebben gaan over: 1. Wat de patiënt zelf kan 2. Communicatie tussen dokter en patiënt 3. Het gebruik van medicijnen
	**2. De dokter** Onderwerpen die met de dokter te maken hebben gaan over: 1. De dokter moet veel weten en kunnen 2. De dokter moet weten wat mensen met een verstandelijke beperking nodig hebben 3. De dokter moet erachter komen wat er met de patiënt aan de hand is
	**3. De omgeving** Onderwerpen die met de omgeving te maken hebben gaan over: 1. Hoe de zorg geregeld is 2. Verschillen tussen landen 3. Samenwerking tussen dokters

4. De gevolgen

Onderwerpen die met de gevolgen van de zorg te maken hebben gaan over:

1. Mensen met een verstandelijke beperking hebben een slechtere gezondheid
2. Mensen met een verstandelijke beperking krijgen minder goede zorg
3. Wat mensen denken over mensen met een verstandelijke beperking

Wat hebben we geleerd?

Er zijn veel onderwerpen die te maken hebben met de medische zorg voor mensen met een verstandelijke beperking.

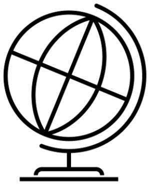
Het is belangrijk om deze onderwerpen te onderzoeken.

Zo krijgen we een goed beeld van de medische zorg.

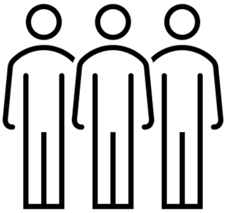
Hoofdstuk 3

Hoe is de medische zorg voor mensen met een verstandelijke beperking geregeld in verschillende landen?

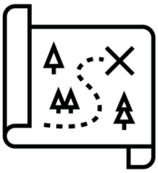
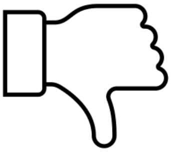
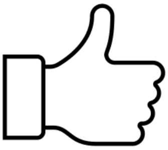
Wat wilden we weten?

	Dit onderzoek gaat over de medische zorg voor mensen met een verstandelijke beperking. We kijken hoe dit geregeld is in verschillende landen. Bijvoorbeeld waar je naartoe moet als je je niet lekker voelt.
?	De vragen van dit onderzoek waren: Hoe regelen verschillende landen de zorg voor mensen met een verstandelijke beperking? Wat is hetzelfde en wat is anders?

Wat hebben we gedaan?

	Mensen uit 13 landen deden mee. Ze hebben opgeschreven hoe de zorg in hun eigen land is geregeld. Dit hebben we met elkaar vergeleken.

Wat zijn we te weten gekomen?

	De zorg is in elk land anders geregeld.
	Landen hebben dezelfde problemen. Deze gaan over: 1. Dat mensen met een verstandelijke beperking minder makkelijk zorg krijgen 2. Dat mensen met een verstandelijke beperking minder goede zorg krijgen 3. Dat wat er bedacht is om de zorg te verbeteren niet wordt gebruikt 4. Dat het niet duidelijk is hoeveel mensen met een verstandelijke beperking er zijn en welke zorg ze krijgen
	Door deze problemen hebben mensen met een verstandelijke beperking minder goede gezondheid en zorg.
	In sommige landen worden er goede dingen gedaan om de zorg te verbeteren. We kunnen daarvan leren.

Wat hebben we geleerd?

💡	Landen hebben dezelfde problemen in de zorg voor mensen met een verstandelijke beperking.
❗	Het is belangrijk om met andere landen samen te werken. Zo kunnen we de zorg voor mensen met een verstandelijke beperking verbeteren.

Hoofdstuk 4

Welke zorg geeft de arts voor verstandelijk gehandicapten?

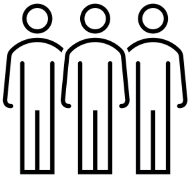
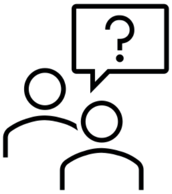
Wat wilden we weten?

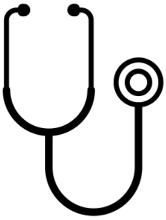
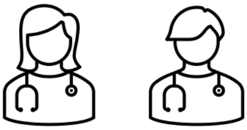
	Dit onderzoek gaat over de medische zorg die de arts voor verstandelijk gehandicapten (arts VG) geeft op de AVG praktijk in Nijmegen. De arts VG kan goed zorg geven aan mensen met een verstandelijke beperking. Op de AVG praktijk in Nijmegen werken artsen VG.
	Huisartsen vinden dat ze niet altijd goede zorg kunnen geven aan mensen met een verstandelijke beperking. De arts VG kan de huisarts dan helpen. We weten nog weinig over hoe de zorg van de arts VG eruit ziet.
	De vraag van dit onderzoek was: Welke zorg geeft de arts VG op de AVG praktijk in Nijmegen? We keken naar: 1. Waarom mensen naar de AVG praktijk komen 2. Welke gezondheidsproblemen deze mensen hebben 3. Welke dokters betrokken worden

Wat hebben we gedaan?

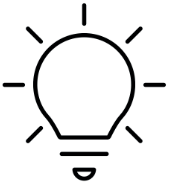
	We hebben gegevens bekeken van 128 patiënten die naar de AVG praktijk zijn geweest.

Wat zijn we te weten gekomen?

	91 patiënten kwamen voor met een klacht. 37 patiënten kwamen voor een jaarlijkse gezondheidscontrole.
	**1. Waarom mensen naar de AVG praktijk komen** Veel mensen kwamen naar de AVG praktijk met psychologische klachten. Dit zijn klachten die te maken hebben met gevoelens, gedachten of gedrag. Bijvoorbeeld je somber of eenzaam voelen.

	**2. Welke gezondheidsproblemen de mensen hebben** Er worden vaak meerdere gezondheidsproblemen in één patiënt gevonden. Deze problemen worden gevonden op meerdere vlakken.
	**3. Welke dokters betrokken worden** Er werden in totaal 25 verschillende dokters betrokken. Bijvoorbeeld de huisarts of de kinderarts.

Wat hebben we geleerd?

	De problemen van patiënten op de AVG praktijk zijn ingewikkeld. Dat komt omdat er problemen op meerdere vlakken gevonden worden. Bijvoorbeeld in het lichaam, in het hoofd, of in de omgeving om de patiënt heen.
	De arts VG zorgt ervoor dat we problemen vinden die we eerder niet hadden gezien. De arts VG zorgt er ook voor dat de juiste dokters betrokken worden.

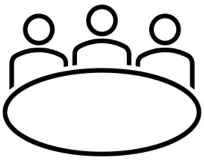
Hoofdstuk 5

Wat vinden mensen met een verstandelijke beperking van de zorg van de arts VG?

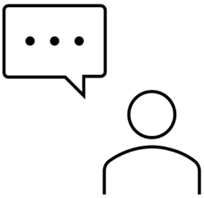
Wat wilden we weten?

	Dit onderzoek gaat over de zorg die de arts voor verstandelijk gehandicapten (arts VG) geeft op de AVG praktijk in Nijmegen. De arts VG kan goed zorg geven aan mensen met een verstandelijke beperking. Op de AVG praktijk in Nijmegen werken artsen VG.
	De vraag van dit onderzoek was: Wat vinden patiënten en hun ouders van de zorg van de arts VG?

Wat hebben we gedaan?

	We hebben gesprekken gehad met 15 mensen die de AVG praktijk hebben bezocht. Hun ouders of begeleiders deden ook mee aan deze gesprekken. De gesprekken gingen over wat ze vonden van de zorg die de arts VG geeft.

Wat zijn we te weten gekomen?

⑦	Er waren 7 onderwerpen die belangrijk waren.
	1. De arts VG moet goede medische zorg geven. Hiervoor moet de arts veel weten over mensen met een verstandelijke beperking. En ook over hun gezondheidsproblemen.
	2. De arts VG moet de patiënt mee laten doen in het gesprek. Daarvoor moet de arts gemakkelijke taal gebruiken.
	3. De arts VG moet niet alleen kijken naar het lichaam, maar ook naar de omgeving van de patiënt. Zo komt de arts met nieuwe ideeën om de klachten van de patiënt op te lossen.

	4. De arts VG moet vriendelijk zijn. Dan voelt de patiënt zich op zijn gemak.
	5. De arts VG moet overleggen met de ouders of begeleider van de patiënt. Zij weten veel over de patiënt.
 	6. De arts VG moet de medische zorg voor de patiënt regelen. Hiervoor moet de arts samenwerken met andere dokters.
 	7. De arts VG moet opkomen voor mensen met een verstandelijke beperking. Zo kan de arts zorgen dat de zorg beter wordt.

Wat hebben we geleerd?

💡	Mensen met een verstandelijke beperking vinden verschillende dingen belangrijk bij hun dokter. Het gaat niet alleen over het geven van goede zorg. Maar bijvoorbeeld ook over het samenwerken met andere dokters en de ouders van de patiënt.
❗	Dokters moeten leren hoe ze goede zorg geven aan mensen met een verstandelijke beperking. Dit onderzoek laat zien wat dokters moeten leren.

Hoofdstuk 6

Discussie

Wat staat er in deze discussie?

	In dit hoofdstuk staat wat we geleerd hebben van dit onderzoek.

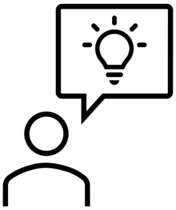
Waar hebben we naar gekeken?

③	We hebben gekeken naar 3 dingen: 1. Hoe de zorg geregeld is 2. Hoe de zorg gegeven wordt 3. Wat mensen vinden van de zorg

Wat hebben we geleerd?

	We hebben geleerd hoe we de medische zorg voor mensen met een verstandelijke beperking kunnen verbeteren. Daarbij is het belangrijk om de drie dingen die hierboven staan mee te nemen.

Wat zijn tips om de zorg te verbeteren?

	Tips om de zorg te verbeteren zijn: 1. Kijk wat we kunnen leren van andere landen 2. Zorg dat dokters meer te weten komen over mensen met een verstandelijke beperking 3. Betrek mensen met een verstandelijke beperking en hun ouders 4. Houd er rekening mee dat veel dingen met elkaar te maken hebben.

Chapter 8

Data management statement

Data management statement

The thesis studies do not fall within the remit of the Medical Research Involving Human Subjects Act (WMO). The local research ethics committee of the Radboud University Nijmegen waived the need for further ethical assessment of the routine data study described in Chapter 4 (2020-6090) and the interview study described in Chapter 5 (2022-16020). Health data was managed according to the General Data Protection Regulation (GDPR). The study protocol of Chapter 4 was preregistered at Open Science Framework and made public after an embargo period. All studies in this thesis were conducted in compliance with the principles of the Declaration of Helsinki and the General Data Protection Regulation. Data collection and storage was performed according to the Findable, Accessible, Interoperable and Reusable (FAIR) principles [1].

Data for the thesis studies were collected by the use of an online group concept mapping method (Chapter 2), by means of a special issue (Chapter 3), by extraction from electronic health records (Chapter 4), and by interviews (Chapter 5). The privacy of the participants in the routine data study described in Chapter 4 was warranted by the use of encrypted individual subject codes, which were created and stored separately from the study data by the Radboud Technology Center (RTC) Health Data of the Department of Primary and Community Care. The privacy of the participants in the concept mapping and interview study described in Chapters 2 and 5 was warranted by the use of pseudonymized data. Participants of the studies described in Chapter 2, 4, and 5 received online or written (easy-to-read) information and informed consent forms to collect and process their data for this study. The sensitivity and confidentiality of the raw qualitative data collected in the studies described in Chapters 2, 3, and 5 makes sharing of the data without compromising confidentiality and privacy impossible. Therefore, consent for sharing of the raw data was not asked from the participants. Published articles used coded data that could not be traced back to the participants. The signed informed consent forms were stored in restricted lockers and will be archived for 15 years after completion of the study.

Data and metadata from Chapters 2, 4, and 5 were archived and published on the Radboud Data Repository. Table 8.1 details where the data and research documentation for each chapter of this thesis can be found on the Radboud Data

Repository. Requests for access will be checked by Jenneken Naaldenberg and a data steward of the Radboudumc against the conditions for sharing the data as described in the signed informed consent. Data from Chapter 3 is available online in the open access JPPID special edition (https://onlinelibrary.wiley.com/doi/toc/10.1111/(ISSN)1741-1130.disabilities-across-globe). All data archived as a DSC remain available for at least 10 years after termination of the studies.

Table 8.1 Findability of the data and research documentation for each chapter of this thesis in the Radboud Data Repository

Ch.	DAC	RDC	DSC	DSC License
2	-	-	https://doi.org/10.34973/a0j2-sw68	CC0-1.0
3	-	-	Open access available from: https://onlinelibrary.wiley.com/doi/toc/10.1111/(ISSN)1741-1130.disabilities-across-globe	-
4	https://doi.org/10.34973/m5sf-a513	https://doi.org/10.34973/98gg-hj86	-	-
5	https://doi.org/10.34973/b0q6-4x60	https://doi.org/10.34973/w85n-6779	-	-

References

1. Wilkinson, M.D., Dumontier, M., Aalbersberg, I.J., Appleton, G., Axton, M., Baak, A. et al. The FAIR Guiding Principles for scientific data management and stewardship. Scientific Data. 2016;3(1):1-9.

Chapter 9

Dankwoord

Dankwoord

Daar is ‘ie dan, mijn proefschrift. Na vier jaar hard werken, maar vooral veel leren, niet al te veel stress en met veel plezier, is het zo ver. Dit proefschrift is niet alleen het resultaat van vele uren onderzoek en schrijven, maar ook van de steun en aanmoediging van een heleboel bijzondere mensen. Die mensen wil ik graag bedanken.

Als eerste natuurlijk mijn begeleidingsteam. Jenneken bedankt voor alle lessen die je me als mijn dagelijks begeleider hebt meegegeven. Jouw scherpe blik heeft mijn onderzoek tot een hoger niveau getild. Je maakte altijd tijd voor me vrij wanneer ik vastliep en gaf gerichte antwoorden op mijn vragen. Dankzij jou kreeg ik altijd op papier wat er in mijn hoofd zat. Mijn deelname aan de Summer School in Valencia was jouw idee en dat bracht mij een onvergetelijke en enorm leerzame ervaring. Geraline, graag wil ik je bedanken voor je vele inzichten en positieve feedback. Door jouw brede visie op mijn onderzoek hebben we er een internationaal tintje aan gegeven dat ik niet had willen missen. Esther, bedankt voor je tomeloze enthousiasme en praktijkverhalen, waardoor ik altijd direct de relevantie van mijn onderzoek terugvond wanneer ik het zelf even uit het oog verloren was. Jouw toewijding aan het vak van de arts VG en de AVG praktijk is inspirerend. Zoals je zelf zei, is ons onderzoek op de AVG praktijk een beetje jouw kindje. Zonder jou was dit niet mogelijk geweest. Tim, jij stapte wat later in het traject in, maar wat ben ik blij dat je erbij was. Onze nuchtere persoonlijkheden pasten goed bij elkaar, wat ervoor zorgde dat ik mijn proefschrift zonder al te veel stress heb kunnen afronden. Daarnaast was er ook altijd ruimte voor een gesprek over ons persoonlijke leven. Bedankt daarvoor!

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Chapter 10

About the author

Curriculum Vitae

Marian Breuer was born on 22 July 1996 in Venlo, the Netherlands. After completing her secondary education, she started the bachelor's program Health Sciences with a specialization in Prevention and Health at Maastricht University. She obtained her bachelor's degree in 2017 and enrolled in the master's program Communication, Health and Life Sciences at Wageningen University. As part of her master program, she worked on projects for the Rotterdam food bank and Sanquin. In July 2019, she graduated with a specialization in Health and Society. Her master's thesis explored palliative care for elderly with dementia and their relatives.

Her positive experiences with research during her studies triggered Marian to start a PhD project at the department of Primary and Community care at the Radboudumc. Her project was part of the Academic Collaborative Stronger on your own feet, a collaboration between the Radboudumc and six residential care facilities for people with intellectual disabilities. Her research focused on the medical care for people with intellectual disabilities, with a special interest in the role of specialized expertise. As part of her PhD training, Marian participated in the 2022 ETC-PHHP summer school on Salutogenesis in practice in Valencia, Spain. In February 2024, she completed her thesis.

Having finished her PhD thesis, Marian continues to work at GGD Limburg-Noord, the public health service of the North of Limburg. She lives in Tegelen.

PhD portfolio of Marian Breuer

Department: **Primary and Community care**
PhD period: **01/10/1996 – 31/01/2024**
PhD Supervisor(s): **Prof. dr. G.L. Leusink, Dr. ir. J. Naaldenberg**
PhD Co-supervisor(s): **Dr. E.J. Bakker-van Gijssel, Dr. T. Pelle**

Training activities	Hours
Courses	
- Radboudumc - Introduction day (2019)	6.00
- RIHS - Introduction course for PhD candidates (2019)	15.00
- Literature review for your PhD (2019)	4.00
- Projectmanagement for PhD candidates (2020)	56.00
- Comparative Health Systems (2020)	16.00
- Radboudumc - eBROK course (for Radboudumc researchers working with human subjects) (2020)	42.00
- Webinar Concept Mapping (2020)	1.50
- Open Science for PhD candidates (2020)	28.00
- Workshop Public Speaking (2020)	1.50
- Poster pitching (2020)	28.00
- Networking (2021)	6.00
- Scientific Writing for PhD candidates (2021)	84.00
- Scientific Integrity for PhD candidates (2021)	14.00
- Radboudumc - Scientific integrity (2021)	20.00
- Workshop Excel for beginners (2021)	1.00
- Advanced conversation (2021)	42.00
- The art of presenting science (2021)	42.00
- Meet the Expert: Twitter for science communication (2021)	1.50
- Meet the Expert: Datavisualization for research (2021)	1.50
- Effective Writing Strategies (2021)	84.00
- Workshop ga eens buiten je boekje (2022)	3.00
- RU - Design and Illustration (2022)	26.00
- What's the next step in my career (2022)	19.00
- ETC summer course (2022)	224.00
- Prepare your defence (2022)	1.25
- Workshop sociale media (2023)	2.00
- Data Management Plan (2023)	1.00
- Kwalitatief interviewen (2023)	16.00
- Research Integrity Round (2023)	1.50

Training activities	Hours
Seminars	
- Symposium Anders dan normaal (2019)	3.00
- ELG Symposium (2019)	4.00
- Symposium Spoedzorg (2020)	3.00
- RIHS webinar Science & Communication (2020)	2.00
- Webinar Online recruitment of study participants (2020)	1.50
- Kwalitatief onderzoek (2021)	14.00
- WHO Long Term Care invitational meeting (2021)	2.80
- Webinar Networking with Crowdhelix (2021)	1.00
- IASSIDD Health inequities during Covid-19 and beyond webinar (2022)	3.00
- Zintern meetings (2020-2023)	6.00
Conferences	
- CaRe days (2021-2023)	21.00
- IASSIDD (2021, oral presentation and workshop)	48.00
- PON PhD day (2021)	4.50
- Special Olympics (2021, invited speaker rountable discussion)	14.00
- PhD retreat (2019, 2022)	30.00
- One day PhD retreat (2022)	8.00
- Focus op onderzoek congres (2023, oral presentation)	16.00
- NHG Wetenschapsdag (2023, oral presentation)	16.00
Other	
- Research Round: Digital Health (2019)	1.50
- Workshop Digital Tools (2019)	4.00
- Programmadag Gewoon Bijzonder (2019-2022, oral presentation)	18.00
- AVG regioavond (2019-2022, three oral presentations)	28.50
- Research dag Academische werkplaatsen (2020 & 2022)	16.00
- Werkconferentie Verrijk de zorg met zinvolle data (2020, oral presentation)	11.00
- WHO LTC group invitational meeting (2021)	2.00
- GMVB Summer School Winter Event (2021)	1.00
- Gewoon Bijzonder - kennisdeling en communiceren over je project (2022)	2.50
- Disability Health Equity Research Network launch meeting (2022)	1.00
- Organizing and hosting 3 international network meetings (2023)	6.00
- Journal club (2023)	28.00
- PhD meetings Intellectual Disability & Health (2019-2023)	80.00
- Guest editor JPPID special edition (2023)	28.00
Supervision of internships / other	
- Meet the PhD week (2021-2023)	150.00
- Presentation and preparing an assignment for medical students (2021)	4.00
- Moving Science course (2022)	8.00
- Supervision of internship (2023)	60.00
Total	**1385.00**

List of publications

Peer-reviewed

Breuer, M. E. J., Bakker-van Gijssel, E. J., Vlot-van Anrooij, K., Tobi, H., Leusink, G. L., & Naaldenberg, J. (2022). Exploring views on medical care for people with intellectual disabilities: an international concept mapping study. *International Journal for Equity in Health, 21*(1), 99.

Breuer, M. E. J., Pelle, T., Leusink, G. L., Linehan, C., Naaldenberg, J. (2024). Synthesis: International perspectives on healthcare for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 21*(2), e12500.

Breuer, M. E. J., Naaldenberg, J., Schalk, B., Heutmekers, M., Pelle, T., Bakker-van Gijssel, E. J., & Leusink, G. L. (2024). Specialized medical care for people with intellectual disabilities: a retrospective cohort study in an outpatient ID practice. *Journal of Policy and Practice in Intellectual Disabilities, 21(3)*, e12516.

Pelle, T., **Breuer, M. E. J.**, Naaldenberg, J., & Linehan, C. (2024). Describing healthcare systems for people with intellectual and developmental disabilities: Global chances and challenges. *Journal of Policy and Practice in Intellectual Disabilities, 21*(1), e12499.

Not peer-reviewed

Naaldenberg, J., **Breuer, M.**, & Gijssel, E. (2020). De organisatie van generalistische medische zorg voor mensen met een verstandelijke beperking in Nederland. *Bijblijven, 36*(1), 28-34.

Breuer, M., Bakker-van Gijssel, E., Vlot-van Anrooij, K., Tobi, H., Leusink, G., & Naaldenberg, J. Hoe wordt de medische zorg voor mensen met een verstandelijke beperking internationaal beschreven? (2022*). Tijdschrift voor Artsen Verstandelijk Gehandicapten. 14*(4), 141-144.

Kampen, J. K., Tobi, H., Hagenaars, J., & **Breuer, M.** (2024). The Validity of Content Mapping: Let’s Call a Spade a Spade. *Research square.*

Published conference abstracts

IASSIDD 6th European Conference (2021)

Breuer, M., Bakker-van Gijssel, E., Vlot-van Anrooij, K., Leusink, G., & Naaldenberg, J. (2021). Towards a shared conceptualization of medical care for people with intellectual and developmental disabilities: A concept mapping study. *Journal of Applied Research in Intellectual Disabilities, Special Issue: Proceedings of the 6th IASSIDD Europe Congress: Value Diversity*. *34*(5), 1294.

Breuer, M., Leusink, G., Naaldenberg, J., Bakker-van Gijssel, E., Schuengel, C. (2021). HealthIDea: Connect, share and learn about healthcare and medical care for people with intellectual and developmental disabilities worldwide. *Journal of Applied Research in Intellectual Disabilities, Special Issue: Proceedings of the 6th IASSIDD Europe Congress: Value Diversity*. *34*(5), 1302.

Bakker-van Gijssel, E. and **Breuer, M.** (2021). Insight from electronic health records in the intellectual disabilities outpatient clinic. *Journal of Applied Research in Intellectual Disabilities, Special Issue: Proceedings of the 6th IASSIDD Europe Congress: Value Diversity*. *34*(5), 1321.

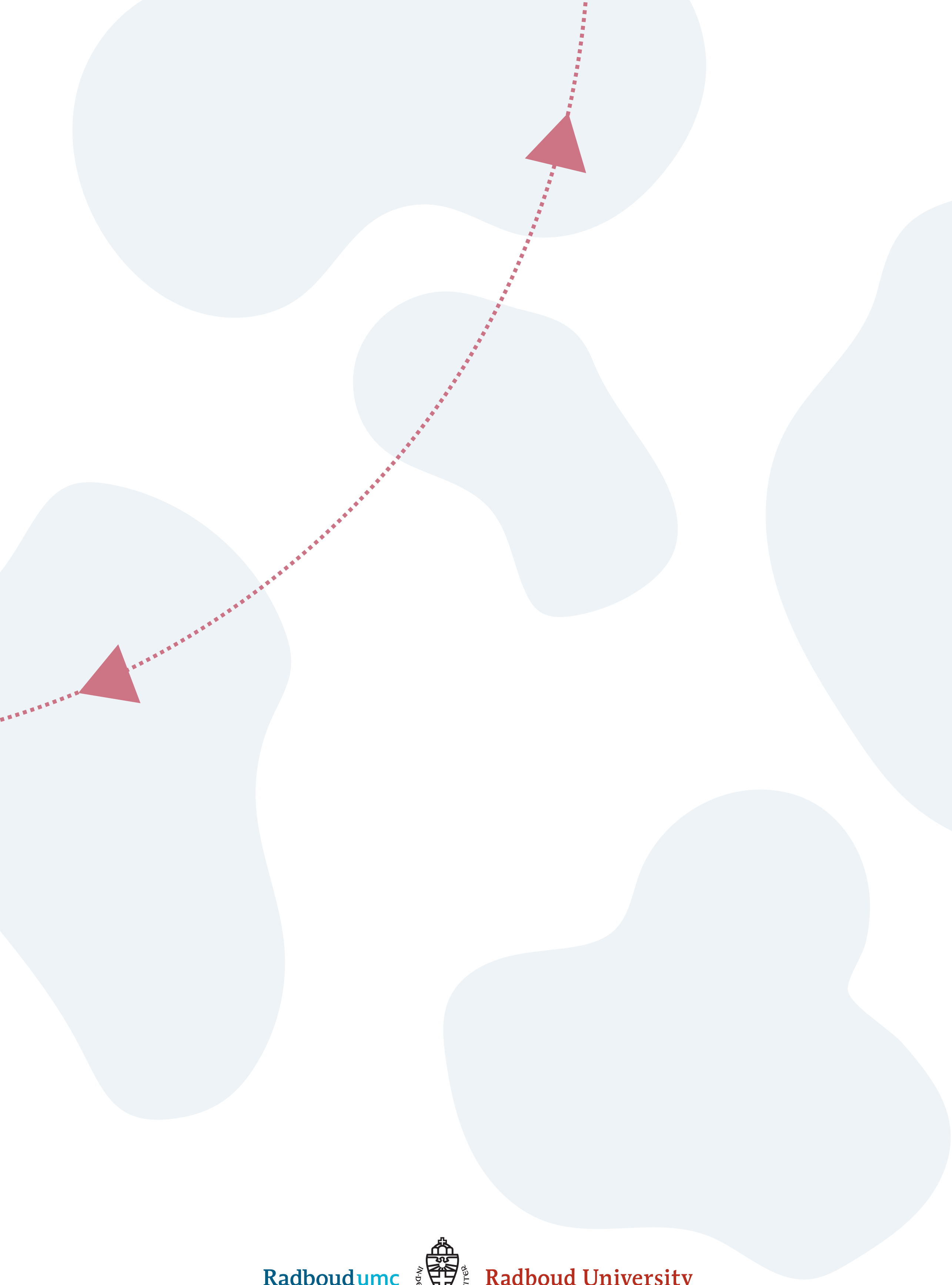
Focus op Onderzoek (2023)

Breuer, M. (2023). Specialistische medische zorg voor mensen met een verstandelijke beperking: een AVG praktijk in Nijmegen. Available from https://focusoponderzoek. verslagvandedag.nl/sites/default/files/u-7/files/2023-06/Overzicht%20Abstracts%20Focus% 20op%20Onderzoek%202023.pdf, 2.

IASSIDD 17th World Conference (2024)

Breuer, M., Bakker-van Gijssel, E., Pelle, T., Heutmekers, M., Schalk, B., Naaldenberg, J., & Leusink, G. (2024). The role of specialized medical ID expertise in the medical care for people with ID. *Journal of Intellectual Disability Research, 68*(7), 770.

Breuer, M., Pelle. T., Leusink, G., Linehan, C., & Naaldenberg, J. (2024). Reimagining international health research: exploring ideas for international collaboration on improving healthcare and access to healthcare. *Journal of Intellectual Disability Research, 68*(7), 649.



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