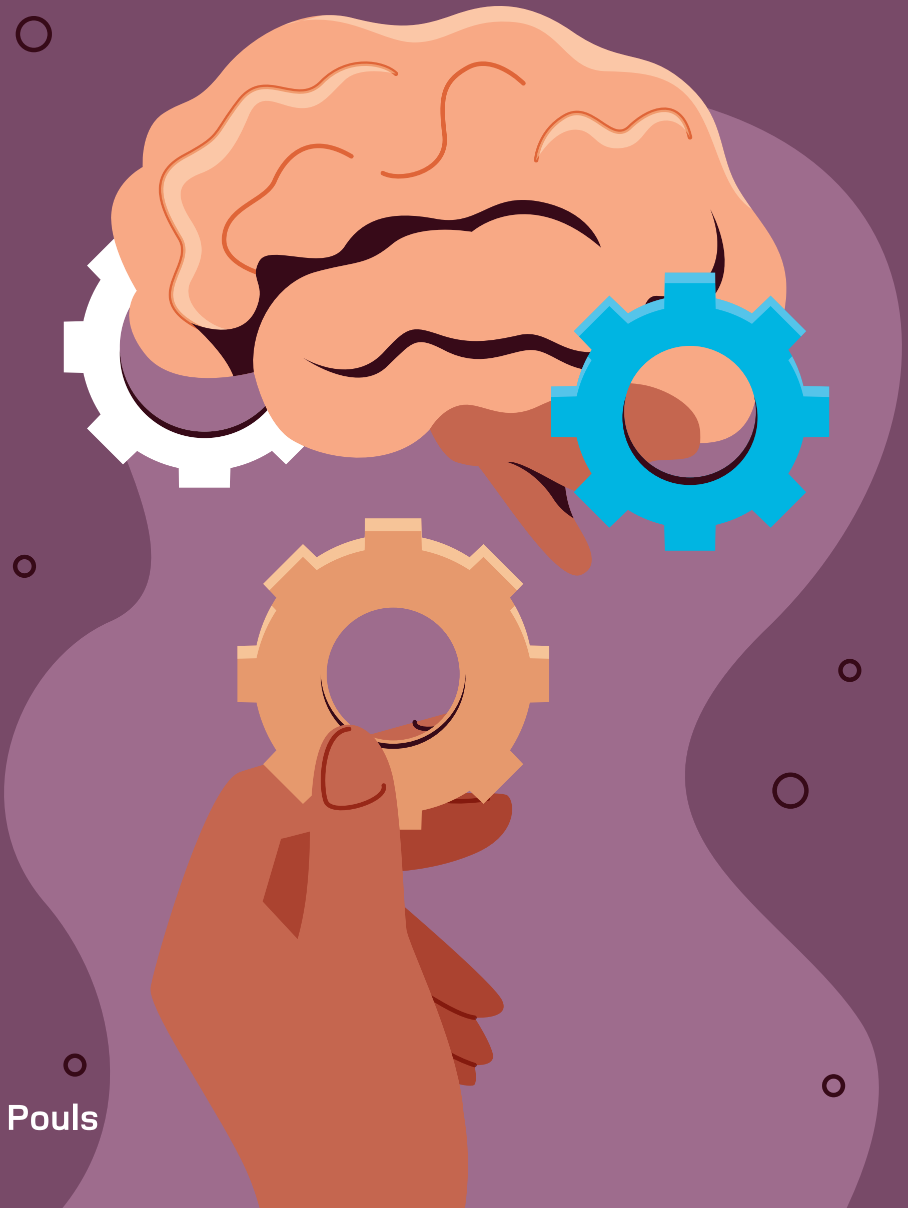
# Primary mental healthcare for people with mild intellectual disabilities

## Opportunities upstream



Katrien Pouls

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## Colophon

This research was carried out within the Radboudumc Graduate School and the academic collaborative Intellectual disability and Health ‘Stronger on your own feet’, a collaboration between Radboudumc, Dichterbij, Driestroom, ‘s Heeren Loo, Koraal, Philadelphia, and Siza.

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# Psychische zorg voor mensen met een lichte verstandelijke beperking in de huisartsenpraktijk

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aan de Radboud Universiteit Nijmegen
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volgens besluit van het college voor promoties
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door

Katrien Petronella Maria Pouls
geboren op 1 augustus 1978
te 's Hertogenbosch

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# Primary mental healthcare for people with mild intellectual disabilities

## Opportunities upstream

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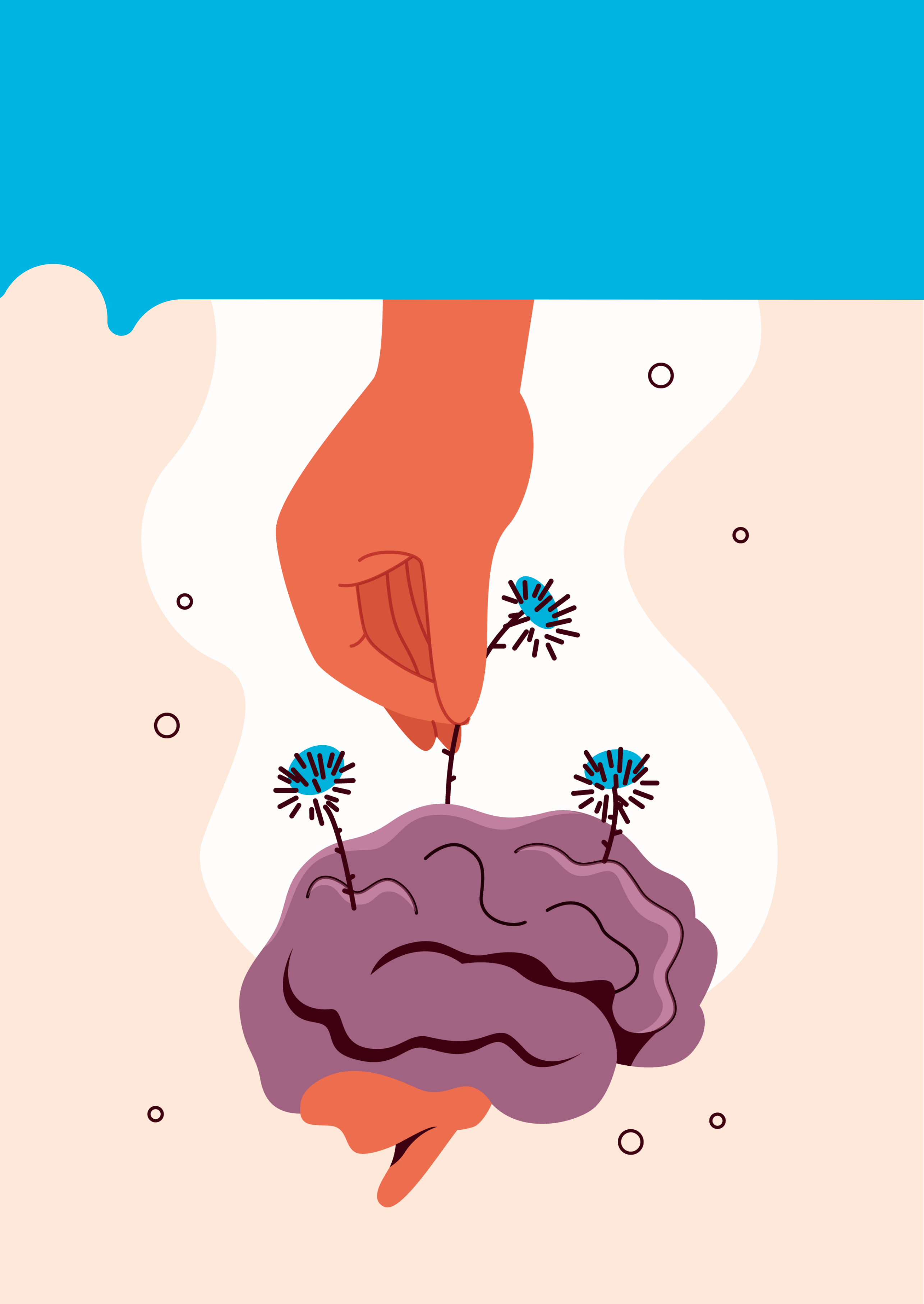

# Chapter 1

## General Introduction

> *There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in.*
>
> Desmond Tutu

## An illustrative patient case that inspired me to undertake this thesis

As ID physician, I met Bob (fictitious name), a 30-year-old man with mild intellectual disabilities (MID), in 2018. Bob had a difficult childhood, with a chronically depressed mother and a father who was often absent, being an international truck driver. He started living on his own at the age of 17. A few months after his father passed away, he had his first depressive episode at the age of 19. In the following 10 years, he was hospitalized several times for depressions, delusions, poor self-care, and substance abuse. In the discharge papers, he was described as an unmotivated patient who did not adhere to therapy. In between the admissions, he lived alone in an apartment, worked on and off in construction, had no contact with his mother, had hardly any friends, and developed financial debts. His MID was not diagnosed until after the third admission at the age of 25. After the last admission, in 2018, he came to live in a group home of the intellectual disability (ID) facility for which I worked.

Since then, things have slowly improved. Bob seems to thrive in the clarity and structure of the group and the proximity of guidance and support. Although he sometimes has trouble adhering to the house rules and uses cannabis now and then, his mental health is stable. His use of psychotropics has largely phased out, contact with his mother has been restored, and his finances are back in order. He works five days a week at a sheltered workplace, is saving for his motorcycle licence, and, in the long term, he wants to live more independently.

At first glance, this appears a success story. However, it had me puzzled. Why did Bob have struggle for so long before receiving the care and support he needed? Could more tailored care and support at an earlier stage of his life, upstream so to speak, have prevented the need for more intensive forms of mental health (MH) and ID care? Would his life story then have unfolded differently, more positively? Bob's story, and many similar life stories that I encountered in my medical practice as ID physician, inspired and motivated me to start this research and, quoting Desmond Tutu, to go upstream and find out why these people are falling in.

## Mild intellectual disability

People with MID are characterized by significant limitations in both intellectual functioning and adaptive skills, with onset during childhood. [1] Intellectual functioning refers to general cognitive capacities and includes reasoning, abstract thinking, problem solving, and scholar skills. Adaptive skills consist of conceptual skills such as use of money and the concept of time, social skills like social problem solving and communication, and practical skills like self-care and use of public transport.

Despite no intelligence quotient (IQ) range being included in the current Diagnostic and Statistical Manual of Mental Disorders definition of MID, [1] the 50–70 IQ range is often adhered to internationally. However, in some countries, including the Netherlands, a broader definition of MID is used. This broader definition includes an IQ range from 50 to 85 with such limitations in adaptive skills that support is needed to function adequately in daily life. [2] It is estimated that 6.4% of the Dutch population have MID according to this broader definition, amounting to 1.17 million people. [3] For this thesis, we used this broad MID definition.

Because of their cognitive and adaptive limitations, people with MID are vulnerable to experiencing challenges in multiple domains of life. Just like people without ID, people with MID have the desire to function as fully and as independently as possible. This may be a challenge in today's increasingly complex society. Complicated application procedures for care and benefits, less availability of simple jobs, higher demands in education, and lack of support networks are examples of factors that create a more complex society for people with MID. [2] These factors are reflected in people with MID having a much lower employment rate, an income level that is more often below the poverty level, higher prevalence of (MH) health problems, and a smaller network of family and friends, and being incarcerated more often, compared with the general population. [4]

Besides this accumulation of challenges in various life domains, their vulnerability may be further enhanced for several reasons. First, the MID and the accompanying limitations may not be directly visible to outsiders, including care professionals. In addition, people with MID may find it difficult to discuss their MID with others, or are themselves insufficiently aware of their cognitive and adaptive limitations. Failure by care professionals to take the MID into consideration in communication or support can lead to overburden and stress in patients and to the provision of inadequate care and support. Furthermore, people's own denial of their MID, a desire to please, gullibility, and naivete increase their vulnerability and may be barriers to obtaining the appropriate support. [4]

Because of these limitations, challenges, and vulnerabilities, people with MID need the appropriate support and care to be able to live as fully as possible. However, many people are not known in the MID service system and may thus lack this (professional) support.

## Mild intellectual disabilities and mental health problems

Up to a third of adults with MID experience MH problems. This is double the general population estimates. [5] In particular, psychotic disorders, mood problems, and anxiety are highly prevalent in people with MID. [5-7] Specific genetic disorders, stressful life events, lack of adequate coping strategies, low socioeconomic status, and lack of emotional support are associated with MH problems and are more prevalent in people with MID, compared with the general population. [4, 8, 9] The high prevalence of MH problems in people with MID is worrying, given that having either an ID or an MH disorder puts a high burden on people's lives and on that of their families, and the combination is likely to be even more burdensome. [10, 11]

### Organization of primary mental healthcare

In the Netherlands, just like in most other countries with a primary care model, the general practitioner (GP) plays a pivotal role in primary healthcare, including MH. All Dutch inhabitants, including those with MID, are registered with a local general practice. An exception is a relative small group of people with MID who receive long-term care and support, including primary care, through ID-care facilities. [12] GPs are the first point of contact for people, with and without MID, with questions concerning their MH. Their care provision constitutes both a demand-driven approach in assessment, treatment, and follow-up of MH problems and a more proactive approach aimed at prevention by identifying risk factors for MH problems and providing health education. [13] The GP provides primary MH care and is a gatekeeper to specialist care. In this regard, the GP plays an important role in integrative MH care, where task-sharing with other care providers is seen as a prerequisite for good MH care. [14] In the Netherlands, all costs involved are covered by mandatory health insurance. In providing MH care, the Dutch GP is generally supported by a mental health nurse practitioner (MHNP). [15] An MHNP works under the supervision of the GP, plays a role in the assessment of MH symptoms, and gives short periods of treatment and support to people with mild MH symptoms. In 2016, an MHNP was employed in 87% of all Dutch primary care practices. [15]

When deemed necessary, the GP can refer to different care professionals and (MH) services. In the Netherlands, MH services are subdivided into basic MH services for mild and low-complex MH problems and advanced MH services for more severe and complex MH disorders. [16] Care provided by either basic or advanced MH services is covered by the mandatory health insurance. Additionally, for less intensive forms of (MH) care and support in the home setting, the Dutch GP can refer to the local authorities' community teams. These costs are covered under the Social Support Act, when indicated by the authorities. [12]

When dealing with patients with MID, the GP can refer to more specialized care. In the Netherlands, these are services such as an ID physician or MH services specialized in people with ID. However, their availability is limited because of the still low numbers of these specialized forms of care, and sometimes services are not fully covered by the health insurance and additional financing must be applied for at the Dutch Care Needs Assessment Centre (CIZ, Centrum Indicatiestelling Zorg). [12]

### Concerns regarding the quality of (primary) mental healthcare for persons with mild intellectual disabilities

Research shows an increase in people with complex MH problems consulting their GP. [17] This will most probably include people with MID as well, although exact numbers are unknown. Adequate primary MH care is essential to prevent diagnostic delay and ensure appropriate treatment and timely referral to other care providers, such as general MH services. [13] However, there are several reasons for concern regarding the quality of (primary) MH care for people with MID. The reasons in the Netherlands align with concerns internationally. [17-20]

First, although GPs acknowledge their role in MH care, they do not always feel equipped to provide the necessary care to the general population with MH problems[21, 22] and feel even less competent providing care to people with a combination of MH problems and ID. [23] In addition, they experience poor access to (specialized) MH services for their patients. [23 24] Previous research shows that long-term MH conditions, like psychosis and depression, are poorly managed in primary care, and psychotropic prescriptions exceed the number of reported MH problems, suggesting inappropriate treatment for people with ID. [6, 25]

Second, both MID and MH problems may be missed in primary care. Previous research shows that the MID may stay unnoticed in primary care because the MID is never officially established or not recognized by the GP. [26] The MID can therefore not be taken into account in the patient's communication and the GP's assessment of potential MH problems. In addition, when the MID is known, the risk of diagnostic overshadowing appears; the MID or the MH problems may be missed when symptoms are attributed exclusively to either of these specific disorders, though both states are present. [27, 28]

Furthermore, after patients' referral to MH services by the GP, the quality of MH care to people with MID is not assured. People with MID may be excluded from certain treatments or even any care at all, because the MH service has insufficient expertise[19] or because treatment modalities are not adapted to people with ID. [29] This is concerning, considering that 27 to 67% of patients in MH services are suspected of having MID, depending on the care intensity in the setting. [20] In addition, people with MID report negative experiences with general MH services, including poor accessibility and information provision. [30, 31] Specialized MH services focusing on people with ID are scarce and often have long waiting times. [32]

Inadequate MH care exposes people with both MID and MH problems to the risk of developing more severe or chronic MH problems downstream, being prescribed more psychotropics, and using more services. [33] This leads to increased healthcare costs and reduced satisfaction among both patients and healthcare providers. Therefore, there is an urgency to find opportunities to improve the quality of MH care for this patient group early in healthcare chain, upstream, preferably in primary care. Research on actual insight into the type and prevalence of MH problems, the care provided, and experiences of both patients and care providers in primary care is lacking but would be valuable in uncovering these opportunities.

## Overall aim and research questions

This thesis aims to provide insight into the quantitative and qualitative characteristics of MH care for people with MID, with a main focus on the Dutch primary care setting. It concerns MH care for people with MID whose ID may or may not be known to care professionals. The findings may provide guidance to improve MH care for people with MID, which is the overall aim of this thesis.

The five main research questions are:

1. What has been described about the care for adult patients with both ID and MH problems provided by the GP?
2. What is the prevalence of MH problems in people with MID and the care provided in primary care, compared with that found for people without ID?
3. What is the prevalence of MH disorders in people with MID and care provided in advanced MH services, compared with that found for people without ID?
4. What are patients' experiences, needs, and suggestions for improvement regarding MH care provided in primary care?

5. What are GPs' and MHNPs' experiences, needs, and suggestions for improvement regarding MH care provided in primary care?

## Outline of this thesis

The five studies conducted in the research project are briefly described below to provide an outline of this thesis.

**Chapter 2** provides an overview of the existing knowledge on GP care for people with both ID and MH problems and identifies knowledge gaps and opportunities that may improve primary MH care. For this, we conducted a scoping review, for which relevant publications were retrieved from international scientific and grey literature.

Chapters 3 and 4 provide a quantitative perspective on MH care for people with MID. **Chapter 3** presents an overview of the prevalence of both MH disorders and MH complaints in people with MID, and the primary care provided in terms of consultations and medication prescriptions, compared with people with no ID. For this retrospective database study, we linked a primary care database with a social service information database to identify people with MID who would have been overlooked without data linkage.

After the initial contacts with the GP, some of the people with both MID and MH problems will be referred to advanced MH services by their GP. **Chapter 4** provides an analysis of the prevalence of the range of MH disorders and the MH care provided to people with and without MID in advanced MH services. We conducted a population-based database study by linking an MH service database with the same social service information database as used in Chapter 3.

Chapters 5 and 6 provide a qualitative perspective on primary MH care for people with MID. In **Chapter 5**, we explored patients' experiences and needs regarding the primary MH care that they received. For this qualitative study, we conducted semi-structured interviews among people with MID and a range of MH problems.

**Chapter 6** describes GPs' and MHNPs' experiences, needs, and suggestions for improvement regarding providing MH care to people with MID. Data were collected through focus groups.

Finally, in **Chapter 7**, the main findings of the studies in Chapters 2 to 6 are summarized, discussed, and reflected on. Suggestions for future research and recommendations for daily practice and policy are made.

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# Chapter 2

# Adults with intellectual disabilities and mental health disorders in primary care: a scoping review

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# Abstract

**Background:** General practitioners (GPs) are increasingly confronted with patients with both intellectual disabilities (ID) and mental health disorders (MHD). Currently, the care provided to these patients is found to be insufficient, putting them at risk of developing more severe MHD. Improving the quality of GP care will improve the whole of mental healthcare for this patient group. Therefore, an overview of the content and quality of care provided to them by the GP might be helpful.

**Aim**: To provide an up-to-date literature overview of the care provided by GPs to patients with ID and MHD, identify knowledge gaps, and inform research, practice, and policy about opportunities to improve care.

**Design**: Scoping review

**Method:** Pubmed, PsychINFO, Embase, and grey literature were searched for publications concerning patients with ID, MHD, and primary care. Selected publications were analysed qualitatively.

**Results**: One hundred publications met the inclusion criteria. Five overarching themes were identified: GP roles, knowledge and experience, caregiver roles, collaboration, and a standardised approach. The results show GPs' vital, diverse, and demanding roles in caring for patients with both ID and MHD. GPs experience problems in fulfilling their roles, and gaps are identified regarding effective GP training programmes, applicable guidelines and tools, optimal collaborative mental healthcare, and corresponding payment models.

**Conclusion:** The improvement required in the current quality of GP care to patients with ID and MHD can be achieved by bridging the identified gaps and initiating close collaborations between care professionals, policymakers, and organisational managers.

## Introduction

General practitioners (GPs) are increasingly confronted with patients with both intellectual disabilities (IDs) and mental health disorders (MHDs), caused mainly by a growing need for care and support for people with mild to borderline intellectual disabilities (IQ 55-85) arising from our increasingly complex society. [1] Patients with ID have greater healthcare needs with higher levels of morbidity and premature mortality than patients without ID, [2, 3] a situation to which insufficient quality of healthcare is a substantial contributor. [2] Patients with co-existing MHD form an extra vulnerable group in this context.

Although research shows that MHDs are three to four times more common in people with ID than in the general population, [4, 5] primary and secondary care provided to these patients is insufficient. [6-8] This is the consequence of inadequate identification of IDs and MHDs, communication difficulties, atypical presentation of disorders, and a lack of assessment tools and treatment modalities specifically adapted to people with ID. [9-11] But also the poor accessibility to (mental) health services for patients with ID is described as an important contributing factor. [12, 13] Consequently, patients with both ID and MHD are at risk of developing more severe or chronic MHDs, are prescribed more psychotropic medication, and use more services. [14]

In many countries, GPs are often the first care providers contacted by these patients. Their care provision constitutes both a demand-driven approach in assessment, treatment, and follow-up of symptoms and disorders, and a more proactive approach aimed at prevention by identifying risk factors and providing health education. Adequate primary care, including both these approaches, is essential for patients with both ID and MHD to prevent diagnostic delay and ensure appropriate and timely referral and early personalised treatment. [15]

Although studies are increasingly published on expanding knowledge and skills within mental healthcare and ID care, [16, 17] reported practices are mostly small scale and lack an orientation on primary care. This is surprising and disturbing, considering GPs' important position in the mental healthcare system and the growing demands of this patient group.

We conducted a scoping review to enhance the level of knowledge and provide an up-to-date overview of GP care for patients with both ID and MHD, identify knowledge gaps, and inform research, practice, and policy about opportunities to improve care.

## Methods

This review follows Arksey and O'Malley's [18] framework for scoping reviews, revised by Khalil et al., [19] and describes methods and results in line with the PRISMA Extension for Scoping Reviews checklist. [20]

### Defining the research question

The guiding research question was: What has been described about the care for adult patients with both ID and MHD provided by GPs? The key concepts are defined in Supplementary Table 2.1.

### Retrieving relevant publications

Relevant publications were identified using a three-step literature search. [19] Firstly, Pubmed, PsychINFO, and Embase were explored (01/1994 and 09/2019), using search terms pertaining to 'primary care' and 'intellectual disability', informed by an information specialist (Supplementary Table 2.1). Selected publications were searched for keywords missed in the initial search. This yielded an additional search string for 'ID' (Supplementary Table 2.1). Secondly, relevant publications were retrieved from grey literature, using the recommendations of 'Grey Matters'. [21] Common search terms for 'primary care' and 'intellectual disability' in English and in Dutch were used (Supplementary Table 2.1). Thirdly, the reference lists were searched for additional relevant publications.

### Selection of publications

Duplicates were removed, and the first author (KP) performed a first selection on title and abstract. About 20% was double screened by a second independent researcher (MK or MM). The full texts were then screened by the first author (KP) and a second independent researcher (MK, MM). Any judgement differences were discussed to reach consensus within each review pair. When consensus could not be reached, the third reviewer became involved to resolve outstanding conflicts. Publications were included if they concerned adults with an ID, an MHD, and primary care following the prepared definitions. Other criteria were: (i) adult focused (≥ 18 years); (ii) originating in Western European and Anglo-Saxon countries where GP's have a comparable role as gatekeeper for more specialised mental healthcare; (iii) available in full text; and (iv) available in English or Dutch. There was no selection on publication type. Publications on forensic primary care were excluded because they concern a selective group of patients beyond the scope of this review.

### Presentation and collation of the data

A standardised data extraction form was developed to guide data charting for descriptive analysis, including publication year, country of origin, publication type, domain, and the care element(s) described. The selected publications' content was qualitatively analysed using conventional content analysis [22] supported by ATLAS.ti software (version 8.4). This process involved repeatedly reading the articles, identifying relevant text fragments, and inductively generating codes related to the research question. All coding was conducted by two researchers independently (KP, MK). Differences in coding were discussed to reach consensus. Codes were then sorted depending on how they were related. From this, major themes were developed and organised. This iterative process was followed critically by the research team, and key findings were discussed relating to the study's purpose and implications for future research, practice, and policy.

## Results

### Descriptive results

Figure 1 presents the publication selection process. One hundred publications were included for final analysis (Supplementary Table 2.2). The publications' main domains were ID care (39%) and primary care (34%). The number of yield publications increases steadily over de years. In total 46% of the publications described a scientific study, none of which is a randomised controlled trial. Figure 2 presents the overview of relevant characteristics of included publications.

## Prevalence of mental health disorders in primary care

The publications on register-based cohort studies report that people with ID have a higher risk of MHDs than patients without ID. [23-26] Primary care databases show a prevalence of MHDs in adult patients with ID ranging from 21 to 34%. [4, 23, 25-27] GPs' screening of patients with ID or MHD identified 33–71% of patients as having a possible MHD and needing further medical assessment. [28-31] Severe mental illnesses such as schizophrenia, bipolar disorder, and psychosis are more prevalent in patients with ID. [3, 4, 23, 32, 33] Depression and anxiety are recorded less, [33, 34] equally, [4, 34] or more often, [23] with an earlier age of onset for depression. [35] Smoking, alcohol, and other substance use are less prevalent, [23, 33] but alcohol misuse is more prevalent in patients with ID. [23]

## Thematic results

Thematic analysis revealed five overarching themes: GP roles, knowledge and experience, caregiver roles, collaboration, and a standardised approach. The results are narratively presented accordingly. Box 1 presents the key findings per theme.

### *GP roles*

The publications reveal the GP as key figure in the identification, initiation, and coordination of treatment of patients with ID and MHD. [31, 36-45] Several GP roles in the care for this patient group are described, however, with varying acceptance, experience, and fulfilment among GPs. [42, 46, 47]

The GP roles relate, in the first place, to *prevention of MHDs*, [32, 43, 44, 48, 49] in the sense of a *proactive approach*. This comprises general health promotion and targeted education about healthy living or substance use, [32, 44, 49] but also identification of MHD-provoking risk factors and development of prevention strategies. [31, 43, 48, 49]

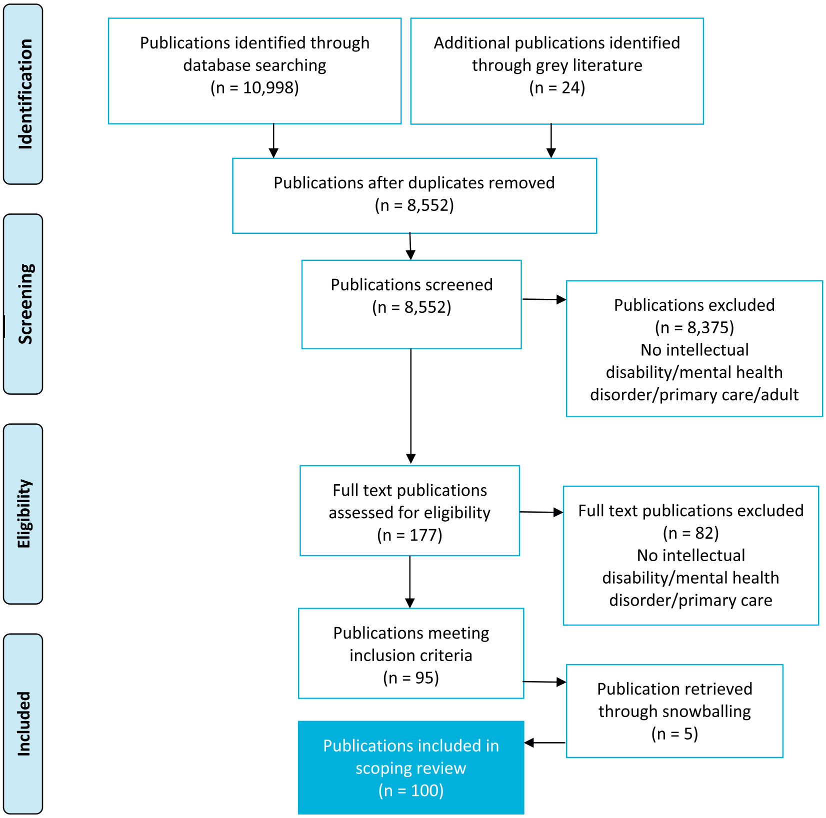

**Figure 2.1.** Flow diagram of study selection process

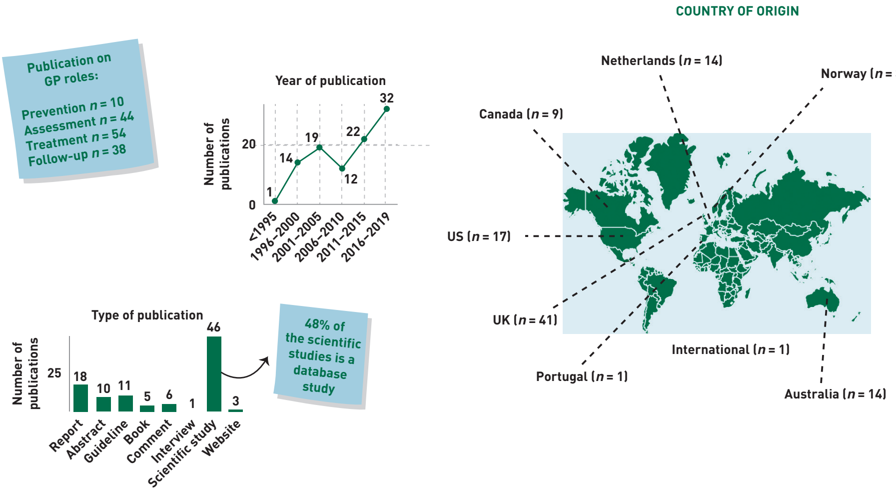

**Figure 2.2.** Overview characteristics of the included publications

Secondly, GPs are expected to fulfil an important role in the diagnostic assessment of MHDs, which is described as challenging for GPs. 50 Indications of inaccurate diagnoses [48, 51] and underdiagnosis in primary care are frequently reported [4, 31, 41, 42, 48, 49, 52-56] and may result in inappropriate care and progression of the disorder to a more severe stage that is less responsive to treatment. [23, 52, 57-59] Overdiagnosis, however, occurs as well, leading to unnecessary prescriptions of medication. [53, 57] Diagnostic failure is seen as related to communication problems, with patients with ID described as less able to label their feelings and communicate their needs, [44, 53, 57, 60-62] resulting in an atypical presentation of symptoms 2[9, 43, 44, 57, 63-65] and a more complicated assessment. [42, 48, 52, 54, 61, 66] It is deemed important for the GP to exclude somatic, environmental, and other causes of symptoms before considering an MHD, [43, 44, 48, 51, 53, 64, 65, 67-73] which requires a holistic, multidimensional approach. [29, 44]

Thirdly, regarding GPs' *treatment role*, it is indicated that GPs should be able to handle less complex MHDs in people with ID. [40, 44, 68] For this patient group the same requirements and treatment guidelines apply as for patients with MHD without an ID, [44, 57, 65, 71, 73] with the necessity to refer patients with more complex disorders to specialised care. [44, 68] GPs prescribe psychotropic medication to a higher number of patients with ID (17–63%) than other patients. [4, 74, 75] In addition, a higher number of patients with ID are reported with psychotropic prescriptions than with recorded MHDs, indicating off-label prescription. [4, 39, 44, 49, 75-80] Behavioural problems are often described as an indication to start medication, [4, 39, 59, 73, 74, 78, 79] specifically in cases of limited access to alternative treatment strategies. [4] Prescribed medication is reported as predominantly long-term medication, [75] and a large proportion (62–70%) is prescribed without a psychiatrist's involvement. [50, 51, 81] Medication prescription can be considered part of a multidisciplinary and holistic care plan; [65] however, in primary practice, GPs are less likely than psychiatrists to provide psychosocial interventions. [72]

Finally, *follow-up* by GPs is considered an essential element in the treatment of patients with ID and MHD. [48, 50, 65, 69, 73, 82-84] It enables the monitoring of treatment responses and possible adverse side effects, leading to early adjustment of the treatment plan. [50, 73] However, a lack of effective monitoring of psychotropic medication by GPs is often described. [28, 42, 51, 55, [74, 81, 85, 86] It is stipulated that this relates to GPs' lack of specific experience and knowledge,[51, 81, 87] uncertainty about who of the involved professionals is responsible for follow-up,[47, 83, 86, 88, 89] patient problems in communicating and presenting (side) effects of medication,[44, 49, 65] and dependence on observations by, and cooperation with, caregivers.[39, 44, 49, 50, 62, 69, 72]

### *Knowledge and experience*

There is general consensus that GPs generally have limited knowledge about, and experience in, managing patients with ID and MHD,[24, 37, 40, 42, 43, 46, 50-52, 58, 66, 69, 81, 87, 90-96] caused by a lack of priority in medical training programmes[37, 40, 43, 50, 52, 58, 66, 93] and a lack of research concerning this patient group.[93] This results in limited evidence-based knowledge[43, 47, 50, 65, 67, 93, 97] and reliance on experience-based knowledge instead.[50] It is indicated that limited knowledge and experience create feelings of insecurity in the GP when addressing patients with ID and MHD,[50] lack of caregivers' confidence in the GP,[52] and insufficient care.[37, 41, 44, 52, 58, 66, 81, 91, 92, 97] Although GPs are interested in more training and education about patients with ID and MHD,[24, 37, 41, 42, 44, 52, 58, 66, 87, 90, 91] in practice it is seen as a challenge to engage them, caused by the small size of the population and the variety of competing medical issues.[58, 70] Publications underline the importance of investment in more research and initiatives for effective training, skill development,[37, 42, 50, 58, 92, 96] and evidence-based guidelines for GPs.[42, 50, 98]

### *Caregiver roles*

In the publications, it is noted that patients with ID and MHDs are often reliant on formal or informal caregivers for receiving care,[23, 43, 49, 57, 62, 69, 72, 99] in the first place, to recognise symptoms of MHDs and seek help.[23, 43, 62, 73, 99] For this task, it is deemed important that caregivers have some knowledge of associated symptoms; however, this knowledge is often lacking.[23, 42-44, 100] Secondly, patients are frequently dependent on caregivers for joint decision making[44] and giving informed consent regarding treatment options like psychotropic medication.[4, 49, 65, 68, 72] Thirdly, caregivers have important roles in the execution of the treatment plan regarding medication adherence and identifying and monitoring possible side effects.[49, 50, 73, 82] A symptoms checklist is mentioned as a helpful tool for caregivers to provide the GP with the information needed.[40, 73] Furthermore, it is noted that the referral process can be complex, and support by caregivers can be essential to prevent delay in care.[96, 100]

In addition, the GP is reliant on caregivers understanding symptom presentation,[29, 43, 44, 53, 57, 60-65] overcoming communication difficulties,[43, 57, 69, 72] and providing additional information.[57, 63, 73] It is indicated that the more severe the ID, the more reliant the GP is on caregivers.[63] Therefore, GPs should determine the key persons in a patient's life[73] and proactively involve them.[49, 72] However, GPs should also realise that some caregivers may give information from their personal perspective, may use different definitions of medical terms than the GP,[44] and may have limited knowledge about the patient[53, 62, 72, 81, 94] or limited communication skills themselves.[42, 44]

### *Collaboration*

The publications emphasise the importance of GPs collaborating with other professionals in the care for patients with ID and MHD. The collaborative partners mentioned are diverse and comprise both medical specialists, for example psychiatrists and pharmacists, and services like community or addiction services. Described areas for collaboration are the assessment of symptoms,[43, 44, 49, 50, 56, 63, 64, 72, 75] level of communicational skills and cognitive functioning,[44, 86] and obtaining advice on referral,[31, 72, 78] treatment,[30, 44, 48-50, 72, 75, 86] or prevention.[49] GPs' options include referral for collegial advice,[31, 48, 72, 94] handing the patient over to other professionals,[44] or joining a multidisciplinary team giving integrative care to the patient.[93, 98, 101] The latter is described as particularly desirable when the patient has a more severe ID or is in a highly complex situation.[39, 44, 99]

Effective collaboration is seen as beneficial for the outcome of mental healthcare in primary care[28, 39, 42, 44, 93, 94, 96, 98, 102] as it is believed to increase the identification of MHDs, improve access to mental healthcare,[98, 101] and reduce hospitalisation[103] and costs.[98, 101] However, inappropriate referrals are reported,[90, 94] resulting from unclear referral options and procedures.[44, 45, 96, 100, 104] Adequate information exchange between GPs and other professionals, in the form of standardised, timely-sent letters, is underlined as important for sharing essential information[38, 62, 94, 105-107] and continuity of care.[105, 106] Yet, audit studies on referral letters and letters from psychiatrists to GPs show that important information is often missing.[62, 94, 100, 105, 107] Finally, it is stated that, in multidisciplinary collaboration, the alignment of responsibilities in treatment and follow-up should be clear.

[44, 68, 108] Particularly in cross-domain collaboration, it may be unclear who is involved, how responsibilities are shared, and how care is financed.[47, 83, 86, 88, 89, 96, 104] It is mentioned that adequate division of responsibilities may depend on the main causal factor(s) of the MHD and may necessitate using care plans and convening case conferences.[68] Responsibilities should be clearly stated in writing and reviewed regularly.[88] Consequently, suggested preconditions for effective collaboration are accessible referral options, clarity about referral procedures, adequate information exchange between the professionals, and consensus on responsibilities.[3, 24, 39, 41, 88, 94, 96, 107]

It is noted as a barrier that, from a historical point of view, primary and secondary care services are separate units culturally,[98] organisationally,[42] and financially.[96, 98, 101] To improve the quality of collaboration, the roles of both GPs and other involved professionals should be defined more clearly,[60, 72] existing models should be evaluated,[42, 109] clinical pathways and/or models should be improved,[24, 42, 109] specialist capacity should be enhanced,[41] and payment models should be re-examined to stimulate collaborative care.[98, 101] Policymakers' involvement in this matter is seen as important.[98, 101]

### *A standardised approach*

In several publications, a standardised approach is seen as a way to improve the quality of care for patients with both ID and MHD.[43-45, 49, 50, 65, 68, 83, 110] Firstly, standardised screening for MHDs gives GPs the opportunity to consider potential mental health issues at an early stage.[44, 49] Secondly, a structured multidimensional approach in the assessment leads to more appropriate and accurate diagnosis, treatment, and referral.[44, 45, 49, 65, 68] Finally, systematic and standardised medication prescriptions and reviews identify potential medication-related problems at an early stage.[43, 50, 65, 83, 110]

Although guidelines and instruments are available to support GPs in applying a standardised approach in the general population, they are often not adapted to patients with ID.[40, 43, 44, 72, 73, 80] Some publications covered specific guidelines for prescribing and/or monitoring medication for MHDs in patients with ID[39, 47, 49, 54, 59, 65, 67, 73, 82] and applicable tools for detecting unmet health needs in patients with ID.[31, 40, 49, 60, 69] It is suggested that GPs are insufficiently familiar with these ID-specific guidelines and tools.[51, 87]

**Box 2.1.** Primary care for patients with both Intellectual Disabilities (ID) and mental health disorders (MHD)

**GP roles**
- Prevention
  - General health promotion
  - Education on potential risk factors for MHDs
  - Identify provoking risk factors for MHDs and act on them
- Assessment
  - Multidimensional assessment of MHDs
- Treatment
  - Treatment of common and less complex MHDs
  - Referral of rare or complex MHDs
  - Prescribing psychotropic medication
- Follow-up
  - Monitoring treatment responses and adverse side effects
  - Coordinating multidisciplinary care

**GPs' knowledge and experience**
- Low priority in research and GPs' educational programmes
- Lack of evidence-based primary care knowledge
- Reliance on experience-based knowledge

**Caregiver role**
- Recognizing symptoms of MHDs and seeking help
- Overcoming communication difficulties
- Providing additional information
- Joint decision making
- Executing and monitoring the treatment plan
- Identifying adverse side-effect of psychotropic medication

**Collaboration**
- Forms of collaboration
  - Collegial advice
  - Handing patient over to another professional
  - Integrative care
- Preconditions for adequate collaboration
  - Referral options with clear procedures
  - Adequate information exchange
  - Consensus on responsibilities
  - Payment models as an incentive for collaboration

**A standardized approach**
- A standardized multidimensional approach may improve the quality of care
- Guidelines and tools applicable to patients with ID

## Discussion

To our knowledge, this is the first scoping review with a focus on patients with both ID and MHD in primary healthcare. GPs are key figures in the care for this specific patient group. They have a broad role that can be demanding in the sense that GPs need specific knowledge, experience, and skills for a relatively small patient group. The publications indicate that current GP care is often of an insufficient standard, as reflected in underdiagnosis of MHDs, overmedication, and lack of effective patient follow-up. Gaps are identified regarding effective training programmes for GPs, applicable guidelines and tools, optimal collaborative mental healthcare, and corresponding payment models. Opportunities for improvement are seen in prioritising and investing in bridging these gaps. This requires the involvement not only of care professionals and scientists, but also of policymakers.

## Strengths and limitations

The first strength of this review is that a robust and widely accepted scoping review method[19] was used to provide a solid overview of the existing knowledge on GP care for patients with both ID and MHD. Secondly, only publications from countries where GPs have a gatekeeper role were included. This results in recommendations that can improve not only the quality of GP care, but the total of mental healthcare for patients with ID. Finally, to prevent dispersion of the results of an already broad research question, we focused on adults and thereby give attention to a vulnerable group that is potentially more overlooked than children.

This review also has limitations. Firstly, a lack of consistency was found in the definition of ID, as many publications did not supply a clear definition of it. This limitation reflects the heterogeneity of the patient group, and results should be interpreted accordingly. Secondly, the publications retrieved in the grey literature search are presumably not perfectly complete, despite the use of the 'Grey Matters' tool[21] and checking references lists. Some publications were not accessible for the research team, and publications could have been missed due to the great diversity of possible sources.

## Comparison with existing literature

The results of this review indicate that patients with ID constitute a small group within the GP population, accounting for the low priority of this group in education and research. [58, 70] However, this claim regarding the proportion of patients is debatable. In the Netherlands, it is estimated that 6.4% of the population have a mild ID. [1] Research in primary care data shows that no more than 0.56% of GPs' clients are registered as having an ID. [23, 34] This could be an indication of GPs' insufficient recognition and underestimation of the size of the ID population. This underestimation is also present in mental healthcare and is a reason for concern. [7] Identification of an ID is essential both for good care provision and for treatment success in MHDs. [14] Helpful ID screening tools have been developed for GPs when they are considering an ID, but further implementation in practice is needed. [111, 112]

Our results revealed two strategies to improve care for patients with both ID and MHD; adequate medical training and applicable evidence-based guidelines and tools. This is in line with previous reports and publications concerning general health issues in patients with ID. [12, 113] It is also suggested that GPs should use the same treatment guidelines for mild or less complex MHDs in patients either with or without ID [44, 57, 65, 71, 73]. However, research to substantiate this is scarce, and research in addiction care shows that alterations in the treatment programmes for substances use disorders are needed for patients with ID. [10] Furthermore, previous research projects have led to practical primary care tools, such as the Psychiatric Assessment Schedule for Adults with Developmental Disability (PASS-ADD). [31, 60] However, these tools are not fully implemented in primary care.

This review identified various kinds of primary care collaborations in which GPs participate, and shows that effective collaboration can improve care; the latter is widely supported and confirmed by the World Health Organization. [114] Our review had an international focus, and the possibilities of multidisciplinary approaches in primary care differ in the various healthcare systems. Within the ambitions and possibilities of the National Health Service, the United Kingdom (UK) sees integrated care systems as an important tool for improving healthcare and for reducing inequalities between different groups of people, [115]and has long-term experience with Community Learning Disability Teams. These multidisciplinary teams provide healthcare and advice to people with ID, GPs, carers, families, and the wider health and social care community. [116] Another example of promising collaboration in daily practice is 'The DD Health Home' in the USA. This care model provides integrative routine care to patients with ID and MHD, including primary care and structural follow-up. [98] Despite these best practices, there is at present limited scientific evidence on the effectiveness of these collaborative (mental) healthcare services for persons with ID.[117] Preconditions for collaborative care, as listed in Box 1, are also recognised in elderly and chronic disease care.[118-120] All these disciplines mention adequate reimbursement as a critical barrier to successful collaboration, and reimbursement needs to be prioritised. Additionally, collaboration is more effective when there is a team vision, shared goals, formal quality processes, and shared ICT information systems.[118, 120] Research in elderly care has revealed that GPs are indispensable in multidisciplinary teams regarding networking activities, integration of care, and showing leadership; the researchers stress that GPs should be made more aware of this, for instance in GP training programmes.[121]

Finally, the results of this review stress the importance of the GP collaborating with caregivers. Remarkably, none of the included publications focused on patients' needs in their contact with the GP, although research shows that people with ID prefer to be less reliant on caregivers in GP consultation and argue for an improvement of the accessibility of health services.[13, 122, 123] The UK NICE guideline 'Mental health problems in people with learning disabilities: prevention, assessment and management' gives special attention to the involvement of people with ID and their caregivers in organizing their care. In addition, this guideline covers MH care in a holistic way in different UK settings, and may serve as an example for other countries.[124]

### Implications for research and/or practice

Improvement of care for patients with both ID and MHD needs to be prioritised, justified by the limited quality of care and the substantial size of this patient group. This improvement cannot be achieved by GPs and their collaborative partners alone. It requires adaptations on both the organisational and the political level. However, it remains important to actively engage GPs to ensure that suggested strategies are applicable and feasible in daily practice.

Diverse improvement strategies are advisable. Firstly, it is important to invest in effective, frequently recurring post-curriculum training programmes for GPs, focusing on more awareness of this patient group, specific knowledge gaps regarding IDs and MHDs, existing tools and guidelines, and GP roles in multidisciplinary teams. Offering training programmes in an interprofessional setting can support the latter and will additionally promote collaboration between care professionals. Secondly, ongoing policy changes, such as the move to integrated care systems in the UK, and best practices like the Community Learning Disability Teams in the UK, provide opportunities for further development of optimal collaborative healthcare models for patients with both ID and MHD. Policymakers should re-examine payment models to create incentives for collaborative care, facilitate shared ICT information facilities, and involve potential users in the development of these healthcare models. Thirdly, although the increase in publication over the recent years is a positive sign, more research is still needed on the effectiveness of existing general mental health guidelines and tools to determine whether they are truly applicable to patients with ID or whether specific alterations are needed. Priority should be given to guidelines and tools on MHD assessment, the prescription of psychotropic medication, and patient follow-up. Finally, further research should focus on the needs of caregivers in supporting patients, as well as on the needs of patients with both ID and MHD and how they can enhance their autonomy in GP contacts.

## Conclusion

This scoping review illustrates GPs' vital roles in the care of patients with both ID and MHD. Current GP care has generally proved insufficient, and improvement strategies are needed in close collaboration with policymakers and organisational managers. Multidisciplinary approaches in primary care – like those in the UK and USA – seem promising, but still lack sufficient scientific evaluation. Investment in education, evidence-based guidelines and tools, and collaborative healthcare models is essential. This, supplemented with enhanced ID identification and attention to the needs of patients and their caregivers, may significantly improve the quality of care for this vulnerable patient group.

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# Supplementary

**Table 2.1.** Overview key definitions and search strings

| | Key definitions |
|---|---|
| **Intellectual disability** | Characterized by significant limitations both in ***intellectual functioning*** and in ***adaptive behaviour*** covering a range of everyday social and practical skills. This disability originates before the age of 18.[1] |
| **Primary care** | Care provided by the general practitioner (GP) and his/her supporting staff |
| **Mental health disorder** | Problems that affect cognitive, emotional, and social well-being not associated with the ID itself according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5. |

| Search strings in electronic databases and grey literature | | | |
|---|---|---|---|
| | | **Primary care** | **Intellectual disability** |
| **PubMed** | original | ("Primary Health Care"[mh] OR "primary care"[all fields] OR "Physicians, Family"[mh] OR general pract*[all fields] OR "family"[ad] OR family pract*[all fields] OR family physician*[tw]) | ((("Intellectual Disability"[Mesh] OR "Mentally Disabled Persons"[Mesh] OR "Developmental Disabilities"[Mesh])) OR (intellectual disab*[tiab] OR intellectually disab*[tiab] OR learning disab*[tiab] OR developmental disab*[tiab] OR developmentally disab*[tiab] OR mental disab*[tiab] OR mentally disab*[tiab] OR mental retard*[tiab] OR mentally retard*[tiab] OR mental handicap*[tiab] OR mentally handicap*[tiab] OR mental deficien*[tiab] OR mentally deficien*[tiab])) |
| | additional | | Developmental delay [tiab] OR Developmental disorder [tiab] OR Intellectual impairment [tiab] OR Learning disorder [tiab] |
| **PsycINFO** | original | (exp Primary Health Care/ OR primary care.af. OR exp Family Physicians/ OR general pract$.af. OR family.in. OR family pract$.af. OR family physician$.mp. OR family medicine/) | intellectual development disorder/ or Cognitive Impairment/ or Developmental Disabilities/ or intellectual disab*.ti,ab,id. or intellectually disab*.ti,ab,id. or learning disab*.ti,ab,id. or developmental disab*.ti,ab,id. or developmentally disab*.ti,ab,id. or mental disab*.ti,ab,id. or mentally disab*.ti,ab,id. or mental retard*.ti,ab,id. or mentally retard*.ti,ab,id. or mental handicap*.ti,ab,id. or mentally handicap*.ti,ab,id. or mental deficien*.ti,ab,id. or mentally deficien*.ti,ab,id. |
| | additional | | Developmental delay .ti,ab,id. OR Developmental disorder .ti,ab,id. OR Intellectual impairment .ti,ab,id. OR Learning disorder .ti,ab,id. |
| **Embase** | original | (exp Primary Health Care/ OR primary care.af. OR exp Physicians, Family/ OR general pract$.af. OR family.in. OR family pract$.af. OR family physician$.mp.) | intellectual impairment/ or Mentally Disabled Person/ or Developmental Disorder/ or mental deficiency/ or Developmental delay/ or (intellectual disab* or intellectually disab* or learning disab* or developmental disab* or developmentally disab* or mental disab* or mentally disab* or mental retard* or mentally retard* or mental handicap* or mentally handicap* or mental deficien* or mentally deficien*).ti,ab,kw. |
| | additional | | Developmental delay .ti,ab,kw. OR Developmental disorder .ti,ab,kw. OR Intellectual impairment .ti,ab,kw. OR Learning disorder .ti,ab,kw. |
| **Grey literature** | English | "Family physician" OR "primary care" OR general pract* | Intellectual* OR learning disab* OR "mental retardation" |
| | Dutch | Huisarts*, eerste* | Verstandelijk*, Geestelijk*, LVB, zwakbegaafd |

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1. Schalock R, Luckasson R, Tasse M. Intellectual Disability: Definition, Classification, and Systems of Supports-12th Edition. 12th ed: American Association on Intellectual and Developmental Disabilities 2021.

**Table 2.2.** Overview included publications

| First author, year | Country of origin | Type of publication | Type of scientific study | Domain | GP care* | Prevalence | Main themes<br>GP roles | Knowledge & experience | Caregivers roles | Collaboration | Standardized approach |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Adams, 2016**[76] | UK | comment | | pharmacology | T, F | | X | | | X | |
| **Ajaz, 2011**[90] | UK | scientific study | cross sectional, survey | intellectual disability care, mental health care | T | | X | X | | X | |
| **Baburaj, 2011**[83] | UK | scientific study | cross sectional, audit | intellectual disability care, mental health care | F | | X | | | X | X |
| **Bakker, 2015**[67] | Netherlands | comment | | general medicine | A,T,F | | X | X | | X | X |
| **Baldor, 2019**[48] | | report | | primary care | P, A, T, F | | X | | X | X | |
| **Balogh, 2010**[103] | Canada | scientific study | cross sectional, register-based cohort study | intellectual disability care | | | | | | X | |
| **BCMH, 2008**[57] | Canada | guideline | | primary care | A,T | | X | | X | X | |
| **Bekkema, 2014**[95] | Netherlands | report | | primary care | | | | X | | X | |
| **Bernard, 1994**[104] | UK | scientific study | cross sectional, survey | mental health care | | | X | | | X | |
| **Birch, 2017**[36] | Australia | report | | primary care | | | X | | | | |
| **Boggon, 2014**[97] | UK | conference abstract | | pharmacist | T | | X | X | | | |
| **Boot, 2018**[86] | Netherlands | scientific study | cross sectional, assessment study | primary care | F | | X | | | X | |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| First author, year | Country of origin | Type of publication | Type of scientific study | Domain | GP care* | Prevalence | GP roles | Knowledge & experience | Caregivers roles | Collaboration | Standardized approach |
| **Bouras, 2003**[125] | UK | scientific study | cross sectional, register-based cohort study | intellectual disability care | | | X | | | X | |
| **Bouras, 2001**[91] | USA | book | | mental health care | T | | | X | | X | |
| **Brooks, 2001**[42] | UK | report | | intellectual disability care | A,T,F | | X | X | X | X | |
| **Buckley, 2003**[88] | UK | scientific study | cross sectional, audit | primary care | F | | X | | | X | X |
| **Carey, 2016**[34] | UK | scientific study | cross sectional, register-based cohort study | primary care | A | X | | | | X | |
| **Cassidy, 2002**[28] | UK | scientific study | cross sectional, assessment study | intellectual disability care | T,F | X | X | | | X | |
| **CDDS, 2006**[64] | Australia | guideline | | primary care | A,T | | X | | X | X | |
| **Chandler, 2012**[109] | Canada | conference abstract | | intellectual disability care | | | | | | X | |
| **Cohen, 1999**[92] | Australia | comment | | general medicine | | | | X | | | |
| **Cooper, 2017**[32] | UK | scientific study | cross sectional, register-based cohort study | intellectual disability care | P,A,T | X | X | | | | X |
| **Cooper, 2015**[23] | UK | scientific study | cross sectional, register-based cohort study | primary care | A | X | X | | X | | |
| **Costello, 2007**[58] | USA | book | | intellectual disability care, mental health care | A,T | | X | X | | | |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **First author, year** | **Country of origin** | **Type of publication** | **Type of scientific study** | **Domain** | **GP care*** | **Prevalence** | **GP roles** | **Knowledge & experience** | **Caregivers roles** | **Collaboration** | **Standardized approach** |
| **Curran, 1996** [43] | USA | book | | primary care | P,A,T,F | | X | X | X | X | X |
| **Davis, 2004** [68] | Australia | report | | primary care | A,T,F | | X | X | X | X | X |
| **Day, 1999** [37] | USA | book | | mental health care | | | X | X | | | |
| **DDPCI, 2019** [54] | Canada | guideline | | primary care | A | | X | | | | X |
| **Dijk van, 2004** [80] | Netherlands | report | | primary care | T | | X | | | | X |
| **Doan, 2013** [74] | Australia | scientific study | cross sectional, register-based cohort study | intellectual disability care | T,F | | X | | | | |
| **Dykens, 2016** [93] | USA | book | | intellectual disability care | | | | X | | X | |
| **Ervin, 2014** [98] | USA | report | | public health | | | | X | | X | |
| **Ervin, 2015** [101] | USA | report | | public health | | | | | | X | |
| **Felce, 2009** [29] | UK | scientific study | cross sectional, assessment study | intellectual disability care | A | X | X | | X | | |
| **Ferreira, 2015** [102] | Portugal | conference abstract | | intellectual disability care | | | | | | X | |
| **Fisher, 2005** [126] | USA | report | | others | | | X | | | | |
| **Fredheim, 2013** [50] | Norway | scientific study | cross sectional, qualitative study | general medicine | A,T,F | | X | X | X | X | X |
| **GGZ, 2018** [44] | Netherlands | guideline | | mental health care, primary care | P,A,T,F | | X | X | X | X | X |

**Table 2.2.** continued

| First author, year | Country of origin | Type of publication | Type of scientific study | Domain | GP care* | Prevalence | GP roles | Knowledge & experience | Caregivers roles | Collaboration | Standardized approach |
|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  | Main themes |  |  |  |  |
| **Glover, 2016** [77] | UK | conference abstract |  | intellectual disability care | T |  | X |  |  |  |  |
| **Glover, 2019** [127] | UK | conference abstract |  | intellectual disability care | T,F |  |  |  |  |  |  |
| **Glover, 2015** [75] | UK | scientific study | cross sectional, register-based cohort study | public health | A,T,F |  | X |  |  | X |  |
| **Gomes, 2019** [87] | Canada | scientific study | cross sectional, register-based cohort study | general medicine | T,F |  | X | X |  |  | X |
| **Granas, 2017** [110] | Norway | conference abstract |  | pharmacist | T,F |  |  |  |  | X | X |
| **Green, 2018** [69] | Canada | report |  | primary care | A,T,F |  | X | X | X | X | X |
| **Gulland, 2016** [128] | UK | comment |  | general medicine | T,F |  | X |  |  |  | X |
| **Hassiotis, 2016** [129] | UK | conference abstract |  | intellectual disability care | T |  |  |  |  |  |  |
| **Hilty, 2004** [85] | USA | scientific study | Pilot | general medicine | T,F |  | X |  |  | X |  |
| **Holden, 2004** [51] | Norway | scientific study | cross sectional, survey | intellectual disability care | A,T,F |  | X | X |  | X | X |
| **Jensen, 2013** [130] | USA | scientific study | cross sectional, register-based cohort study | intellectual disability care | P |  |  |  |  |  | X |
| **Koks, 2019** [131] | Netherlands | conference abstract |  | intellectual disability care |  |  |  |  |  | X |  |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **First author, year** | **Country of origin** | **Type of publication** | **Type of scientific study** | **Domain** | **GP care*** | **Prevalence** | **GP roles** | **Knowledge & experience** | **Caregivers roles** | **Collaboration** | **Standardized approach** |
| **Lennox, 2000** [46] | Australia | scientific study | cross sectional, survey | intellectual disability care | | | X | X | | | |
| **Lennox, 2004** [56] | Australia | report | | primary care | A | | X | | | X | |
| **Lubbes, 2019** [96] | Netherlands | report | | mental health care | T | | | X | X | X | |
| **Lunsky, 2012** [132] | Canada | scientific study | cross sectional, register-based cohort study | mental health care | | | X | | | | |
| **Mahmood, 2000** [81] | UK | comment | | others | A,T,F | | X | X | | X | |
| **Maitland, 2006** [99] | UK | scientific study | cross sectional, register-based cohort study | primary care | | | | | X | X | |
| **Markar, 2002** [38] | UK | scientific study | cross sectional, audit | intellectual disability care | | | X | | | X | |
| **Markar, 1998** [105] | UK | scientific study | cross sectional, audit | intellectual disability care | | | | | | X | |
| **Martin, 1997** [60] | UK | scientific study | cross sectional, assessment study | intellectual disability care | P,A | X | X | | X | X | X |
| **Martin, 1997** [30] | USA | report | | primary care | A,T | | | | | X | |
| **Matthews, 2008** [133] | UK | scientific study | cross sectional, survey | intellectual disability care | A,T | | | | | | |
| **McCoubrie, 2011** [55] | UK | website content | | primary care | A,F | | X | | | | |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **First author, year** | **Country of origin** | **Type of publication** | **Type of scientific study** | **Domain** | **GP care*** | **Prevalence** | **GP roles** | **Knowledge & experience** | **Caregivers roles** | **Collaboration** | **Standardized approach** |
| **McDermott, 1997**[33] | USA | scientific study | cross sectional, register-based cohort study | primary care | | X | | | | | |
| **McDermott, 2005**[35] | USA | scientific study | cross sectional, register-based cohort study | other | | X | | | | | |
| **McGillivray, 2013**[52] | Australia | scientific study | longitudinal, assessment study | intellectual disability care | A,T | | X | X | X | | |
| **Mehnaz, 2010**[106] | UK | scientific study | cross sectional, survey | intellectual disability care | | | | | | X | |
| **Messinger, 1997**[63] | USA | report | | other | P,A,T | | X | | X | X | X |
| **Michael, 2004**[94] | UK | scientific study | cross sectional, audit | intellectual disability care | A,T | | X | X | X | X | |
| **Molyneaux, 1999**[78] | UK | scientific study | cross sectional, register-based cohort study | intellectual disability care | T,F | | X | | | | |
| **Munden, 2002**[70] | UK | scientific study | cross sectional, survey | intellectual disability care | A | | X | X | | | |
| **Nagel van der, 2017**[100] | Netherlands | guideline | | addiction medicine | T | | | | X | X | |
| **NHG, 2019**[134] | Netherlands | guideline | | primary care | A | | | | | | |
| **NHS, 2017**[82] | UK | guideline | | primary care | T,F | | X | | X | X | X |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| First author, year | Country of origin | Type of publication | Type of scientific study | Domain | GP care* | Prevalence | GP roles | Knowledge & experience | Caregivers roles | Collaboration | Standardized approach |
| NVAVG, 2017[108] | Netherlands | guideline | | primary care, intellectual disability care | | | | | | X | |
| Phillips, 2004[66] | Australia | scientific study | cross sectional, survey | intellectual disability care | A,T | | X | X | | | |
| Prater, 2006[71] | USA | report | | primary care | A,T | | X | | | | |
| RCPsych, 2016[65] | UK | guideline | | mental health care | A,T,F | | X | X | X | X | X |
| Regi, 2017[39] | UK | comment | | primary care | T,F | | X | | | X | X |
| Roy, 1997[31] | UK | scientific study | cross sectional, assessment study | intellectual disability care | P,A | X | X | | X | X | X |
| Salomon, 2018[59] | Australia | scientific study | cross sectional, register-based cohort study | primary care | A,T,F | | X | | | | X |
| Saqr, 2018[135] | USA | scientific study | cross sectional, register-based cohort study and qualitative study | other | T | | | | | | |
| Schrojenstein Lantman, 2004[26] | Netherlands | scientific study | cross sectional, register-based cohort study | intellectual disability care | | X | | | | | |
| Schrojenstein Lantman, 2006[25] | Netherlands | report | | primary care | | X | | | | | |

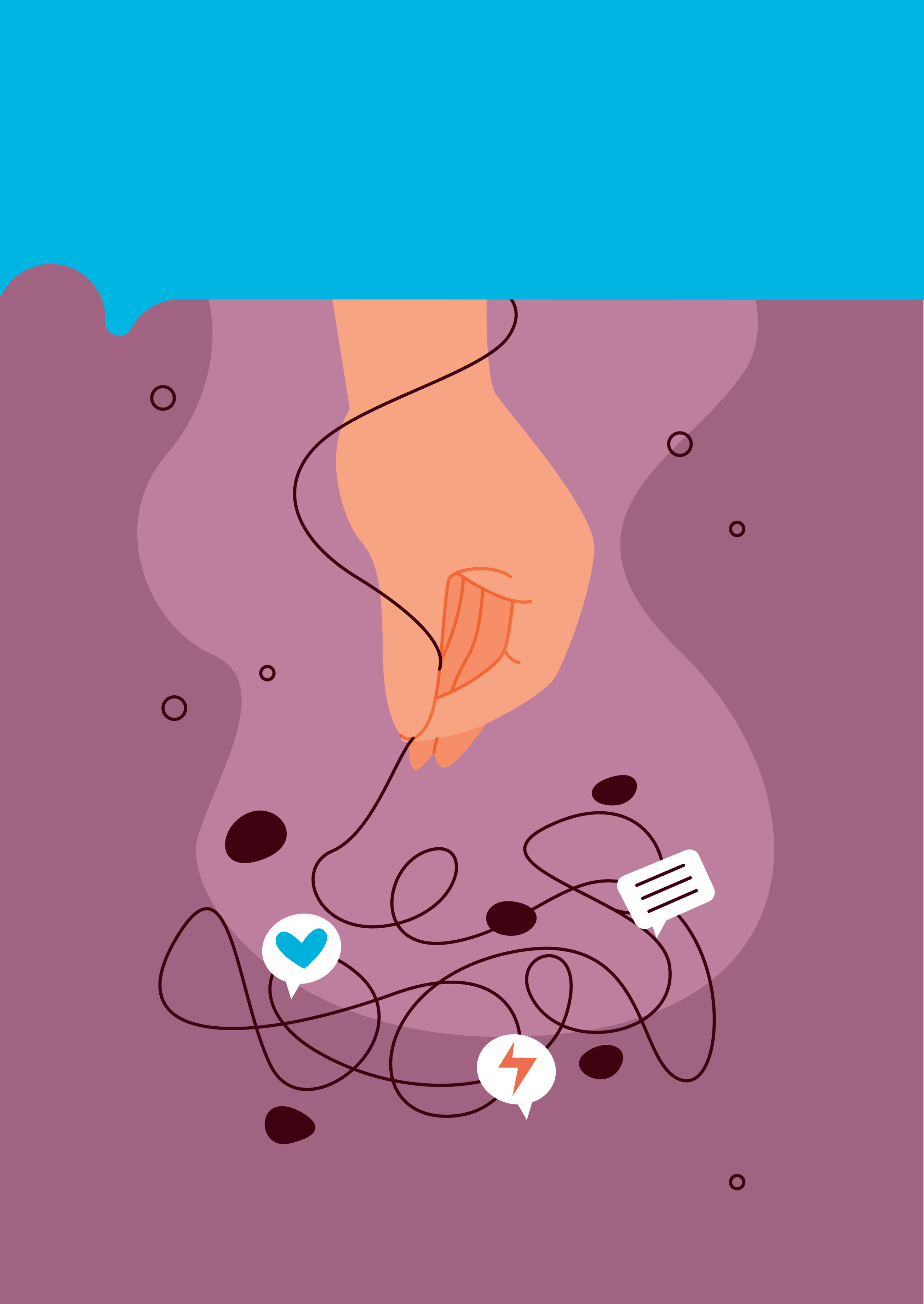
**Table 2.2.** continued

| First author, year | Country of origin | Type of publication | Type of scientific study | Domain | GP care* | Prevalence | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | GP roles | Knowledge & experience | Caregivers roles | Collaboration | Standardized approach |
| **Schrojenstein Lantman, 2000**[27] | Netherlands | scientific study | cross sectional, register-based cohort study | primary care | | X | | | | | |
| **Shankar, 2018**[47] | UK | scientific study | cross sectional, survey | primary care | T,F | | X | X | | X | X |
| **Shankar, 2019**[89] | UK | conference abstract | | intellectual disability care | F | | X | X | | X | |
| **Sheehan, 2017**[84] | UK | scientific study | cross sectional, register-based cohort study | general medicine | T,F | | X | | | | X |
| **Sheehan, 2015**[4] | UK | scientific study | cross sectional, register-based cohort study | general medicine | A,T,F | X | X | | X | X | X |
| **Sheehan, 2015**[79] | UK | conference abstract | | intellectual disability care | T | | X | | | | |
| **Shields, 2013**[24] | Canada | report | | mental health care, addiction medicine | | | | X | | X | |
| **Silka, 2003**[53] | USA | interview | | intellectual disability care, mental health care | A,F | | X | | X | X | |
| **Slater, 2017**[45] | UK | website content | | primary care | A | | X | | | X | X |
| **Straetmans, 2007**[61] | Netherlands | scientific study | cross sectional, register-based cohort study | primary care | A,T | X | X | | X | | |
| **Sullivan, 2018**[49] | Canada | guideline | | primary care | P,A,T,F | | X | | X | X | X |

**Table 2.2.** continued

| | | | | | | | Main themes | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **First author, year** | **Country of origin** | **Type of publication** | **Type of scientific study** | **Domain** | **GP care*** | **Prevalence** | **GP roles** | **Knowledge & experience** | **Caregivers roles** | **Collaboration** | **Standardized approach** |
| **Taylor, 2002** [62] | UK | website content | cross sectional, audit | intellectual disability care | A,F | | X | | X | X | |
| **Thalayasingam, 1999** [107] | UK | scientific study | cross sectional, audit | intellectual disability care | T | | | | | X | |
| **Torr, 2008** [40] | Australia | scientific study | cross sectional, assessment study | intellectual disability care | P,A,T,F | | X | X | X | X | X |
| **Tracy, 2015** [73] | Australia | guideline | | primary care | A,T,F | | X | | X | | X |
| **Trollor, 2016** [41] | Australia | scientific study | cross sectional, register-based cohort study | mental health care | A | X | X | X | | X | |
| **Woods, 2011** [72] | Australia | report | | primary care | A,T,F | | X | | X | X | X |

*P=prevention, A=assessment, T=treatment, F=follow-up



# Chapter 3

# Primary mental healthcare for adults with mild intellectual disabilities: a Dutch database study

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Mastebroek M, Leusink GL.
Primary mental healthcare for adults with mild intellectual disabilities:
a Dutch database study.
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# Abstract

**Background:** General practitioners (GPs) are increasingly confronted with people with both mild intellectual disability (MID) and mental health (MH) problems. Little is known about the type of MH problems for which people with MID visit their GP and the care provided.

**Objectives***:* To identify the type and prevalence of MH disorders and MH-related complaints in people with MID in primary care, and care provided, compared to people without ID.

**Method:** By linking the Netherlands Institute for Health Services Research's primary care databases, comprising electronic health records, with Statistic Netherlands' social services and chronic care databases, we identified 11,887 people with MID. In this 4-year retrospective study, MH-related International Classification of Primary Care (ICPC) codes and care characteristics were compared between people with MID and without ID.

**Results***:* Of the people with MID, 48.8% had MH problems recorded vs 30.4% of the people without ID, with large differences in substance abuse, suicide attempts, and psychosis. Of the MID group, 80.3% were not registered by their GP with the ICPC code mental retardation. GPs provided more care to people with both MID and MH problems compared to people without ID but with MH-problems regarding consultations (median 6.4 vs 4.0 per year) and variety of prescribed medications (median 2.7 vs 2.0 per year).

**Conclusion**: In primary care, the prevalence of MH problems and care provided is high in people with MID. To improve primary mental healthcare for this group, it is essential to increase GPs' awareness and knowledge on the combination of MID and MH.

# Introduction

People with mild intellectual disability (MID), characterised by a significant deficit in intellectual and adaptive functioning, [1] suffer from more mental health (MH) disorders compared to people without intellectual disability (ID), [2, 3] but often do not receive appropriate mental healthcare. [4-8] General practitioners (GPs) are often the first point of contact for people with MH problems and are gatekeepers to specialised mental healthcare services. [9] Prevalence studies in primary care with a specific focus on mental health in people with MID are scarce and focus on established MH disorders only, implicating a lack of knowledge on MH-related complaints (problems presented, no established diagnoses) in primary care.

There are several reasons for concern. Firstly, the identification of both MH disorders [2] and MID are considered problematic. [9, 10] Secondly, people with ID experience general health disparities, including mental health, because of barriers to providing timely, appropriate, and effective primary healthcare. [6] Long-term conditions, like psychosis and depression, are poorly managed in primary care, [5] and psychotropic prescriptions exceed the number of reported MH disorders, suggesting inappropriate prescriptions. [2, 9] Finally, GPs themselves indicate a lack of knowledge and feel insecure about providing the care needed. [9-11]

Still, little is known about the type of MH problems for which people with MID visit their GP and the care they receive. This primary care database study aims to provide an overview of the prevalence of both MH disorders and MH complaints in people with MID and the care provided in terms of consultations and type of medication prescriptions, compared to people without ID. In addition, we study how often the GP adequately codes a person with MID.

# Method

## Study design

For this retrospective database study, we used databases from the Netherlands Institute for Health Services Research Primary Care Database (NIVEL-PCD) [12] and Statistic Netherlands (SN). [13] NIVEL collects healthcare data from routine electronic health register systems from over 400 representative Dutch general practices, covering approximately 10% of the Dutch population. 12 The NIVEL-PCD files provided data regarding personal characteristics, type of health problems, consultations, and medication prescriptions from 1-1-2015 to 31-12-2018. MH problems were identified by ICPC-P codes (International Classification of Primary Care, Psychological category). [14] Medication prescriptions were coded according to the Anatomical Therapeutic Chemical (ATC) classification system up to level 3, the pharmacological subgroup. [15] We included persons 18 years or older in 2015 who remained in the NIVEL-PCD for > 1 year.

## Selection of study objectives

To identify people with MID in the NIVEL-PCD, that database was linked with an SN-MID database. In this database, persons are identified who, in 2015, used services under the Dutch Chronic Care Act, the Disability Benefit Act, or the Sheltered Employment Act with an MID registration (Figure 1).

The comparison group without ID was not shown with an MID in the SN-MID database, had no ICPC code P85 (mental retardation) in the NIVEL-PCD, and was not eligible for ID-specific care according to the SN-Dutch Chronic Care Act database. We matched each individual from the MID group by age, sex, and number of years in the dataset to four random individuals in the group without ID, to allow a robust comparison without overpowering.

We compiled an MID-MH group containing people who had one or more MH problems coded with an ICPC-P other than P85. An additional matched control group was compiled from the group without ID.

This study was reviewed and approved by the Medical Ethical Committee of Radboud University Medical Center (2017-3921) and conducted according to the NIVEL and SN governance code. Results are reported in accordance with the RECORD statement.

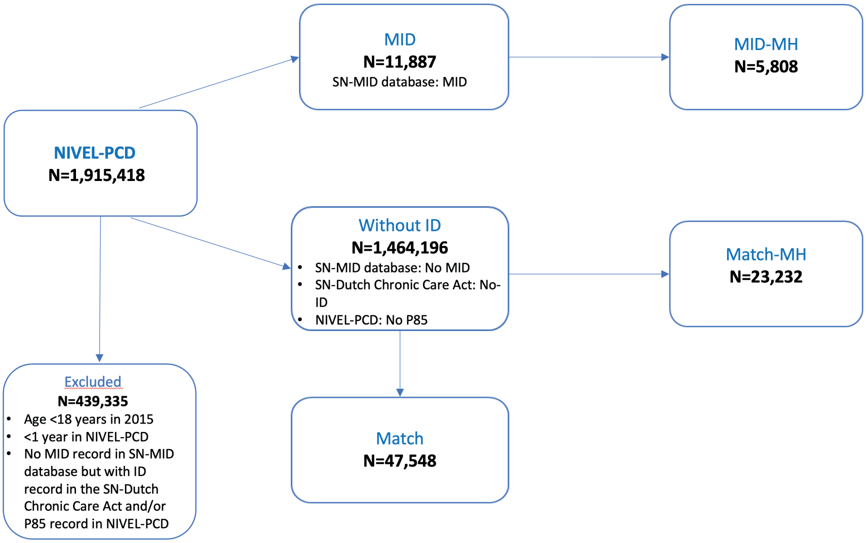

**Figure 3.1.** Composition of groups

NIVEL-PCD: Netherlands Institute for Health Services Research Primary Care Database; SN-MID database: Statistical Netherlands Mild Intellectual Disability database; MID: Group with mild intellectual disability; Without-ID: Group with no-intellectual disability; MH: people who had one or more MH problems coded with an ICPC-P other than P85; Match: Match control group; MID-MH: Group with mild intellectual disability and a mental health problem; Match-MH: Match control group with MH problem.

## Outcomes

The MID was considered ‘registered’ by the GP if the person had a P85 code in the NIVEL-PCD. To calculate the period prevalence of MH problems, MH illness episodes were constructed according to Nielen et al.’s algorithm.[16] MH problems were divided into MH complaints with an ICPC code P1 to P29, and MH disorders with a code P70 to P99. We calculated the prevalence of unique MH problems and the median number of unique MH problems per patient during the research period. Additionally, ICPC codes relating to either psychosis or substance abuse were respectively combined and calculated per patient.

We described the number and type of consultations with a GP and mental health nurse practitioner (MHNP), and unique types of medication prescription categories. For comparison, we also described these for the MID group as a whole and their match group without ID, including people both with and without MH problems. Each person's medication prescription categories were recorded and divided into three selected categories: 1) Total medication use; 2) Psychotropics, including antipsychotics (N05A), anxiolytics (N05B), hypnotics and sedatives (N05C), antidepressants (N06A), psychostimulants (N06B), anti-dementia drugs (N06D), and drugs used in addictive disorders (N07B); and 3) Anti-epileptic medication (N03A), which may be prescribed for specific MH problems. It was not possible to link separate consultations and prescriptions to specific ICPC codes.

### Statistical analysis

Groups were stratified by age groups and sex. Student-T tests, Chi-squared tests, or Mann-Whitney U tests were used to test statistical significance. Logistic regression was used to examine the association with the presence of MID on outcomes, calculating odds ratios (OR) with 95% confidence intervals (95%CI) adjusted for age, sex, and years registered in the database. A p-value < .05 was considered statistically significant. To ensure clinical relevance, only variables with a number of ≥ 30 people were included. All analyses were conducted using SPSS version 25.0.

## Results

### Demographics

In the NIVEL-PCD, 11,887 persons with MID were identified, with a mean age of 37.8 years, of whom 61.7% male, compared to respectively 48.4 years and 48.8% male in the group without ID (N=1,464,196). Of the people with an MID, 80.3% had no ICPC code P85 registration (Table 3.1).

### Period prevalence of MH problems

Of the people with MID, 48.9% had an MH problem over the four-year period, either an MH complaint or an MH disorder, compared to 30.4% in the group without ID. They were significantly younger (37.1 vs 50.6 years) and had a higher number of unique MH problems (median 2.0 vs 1.0). In both groups, the prevalence of MH problems was higher in women. Table 3.2 presents the ICPC codes with the highest OR for both MH complaints and MH disorders (Full overview in Supplementary Table 3.1).

**Table 3.1.** Demographics

| | | MID | Without ID |
|---|---|---|---|
| Total N | | 11,887 | 1,464,196 |
| Men, N (%) | | 7,338 (61.7)$^{**a}$ | 714,136 (48.8) |
| Age, M (SD) | | 37.8 (15.0)$^{**}$ | 49.4 (17.8) |
| Age groups, N (%) | 18–24 | 3,280 (27.6)$^{**b}$ | 133,518 (9.1) |
| | 25–34 | 2,704 (22.7) | 228,303 (15.6) |
| | 35–44 | 1,673 (14.1) | 235,777 (16.1) |
| | 45–54 | 2,150 (18.1) | 290,016 (19.8) |
| | 55–64 | 1,555 (13.1) | 250,964 (17.1) |
| | 65–74 | 525 (4.4) | 325,618 (22.3) |
| Years registered in database, M (SD) | | 2.70 (1.15)$^{*}$ | 2.76 (1.15) |
| ICPC P85 Mental retardation, N (%) | | 2,339 (19.7) | n.a. |

MID: Mild intellectual disability; ID: Intellectual disability; ICPC: International Classification of Primary Care; $^{**}$p < .001, $^{a}$MID compared with without-ID; $^{b}$age group distribution MID compared with without-ID;

More people with MID experienced an MH complaint compared to people without ID (36.2 vs 21.4%; p<.001). Largest differences were seen in the codes ‘limited function and disability’ (P28; OR 38.18, 95%CI 33.34–43.72), ‘specific learning problems’ (P24; OR 6.23, 95%CI 5.14–7.55). In addition, 13.0% of the people with MID had an ICPC code associated with substance abuse (P15–P19), compared to 5.2% in the group without ID.

The prevalence of MH disorders was also higher in people with MID compared to people without ID (25.3 vs 15.0%; p<.001). Large differences were seen in the codes ‘suicide/suicide attempt’ (P77; OR 3.80, 95%CI 3.14–4.60) and ‘psychological disorders, others’ (P99; OR 3.83, 95%CI 3.51–4.18). In addition, 4.2% of the people with MID had an ICPC code associated with psychosis (P71–73 and/or P98), compared to 1.4% in the group without ID.

**Table 3.2.** Prevalence of mental health problems in persons with and without intellectual disability

| | | | MID *N=11,887* | Without ID *N=1,464,196* | OR (95%CI)[b] |
|---|---|---|---|---|---|
| **MH problems (ICPC P1–P99)** | | | | | |
| ≥1 MH problem | N (%) | Total | 5,808 (48,9) | 444,520 (30.4) | 2.50 (2.41–2.59)** |
| | | Men[a] | 3,373 (46.0) | 186,985 (26.2) | 2.55 (2.43–2.67)** |
| | | Women[a] | 2,435 (53.5) | 257,535 (34.3) | 2.43 (2.29–2.58)** |
| | Age | | 37.1 (14.3)** | 50.6 (18.4) | |
| | Median unique MH problems (25–75 percentile) | | 2.0 (1.0–3.0)** | 1.0 (1.0–3.0) | |
| **MH complaint (ICPC P1–P29)** | | | | | |
| ≥1 MH complaint | N (%) | | 4,299 (36.2) | 313,200 (21.4) | 2.39 (2.30–2.49)** |
| | Median unique MH complaints (25–75 percentile) | | 1.0 (1.0–2.0)** | 1.0 (1.0–1.0) | |
| ICPC code[c] N (%) | P28 Limited function/ disability | | 303 (2.5) | 1,018 (0.1) | 38.18 (33.34–43.72)** |
| | P24 Specific learning problem | | 116 (1.0) | 1,424 (0.1) | 6.23 (5.14–7.55)** |
| | P23 Adolescent behaviour symptom/complaint | | 96 (0.8) | 2,362 (0.2) | 3.51 (2.86–4.32)** |
| | P04 Feeling/behaving irritably/angry | | 224 (1.9) | 7,809 (0.5) | 3.47 (3.03–3.97)** |
| | P18 Medication abuse | | 101 (0.8) | 5,967 (0.4) | 3.44 (2.82–4.20)** |
| | P15–P19 Substance abuse, any form | | 1,549 (13.0) | 76,177 (5.2) | 2.64 (2.50–2.79)** |
| **MH disorders (ICPC P70–P99)** | | | | | |
| ≥1 MH disorders | N (%) | | 3,006 (25.3) | 220,298 (15.0) | 2.09 (2.00–2.18)** |
| | Median unique MH disorders (25–75 percentile) | | 1.0 (1.0–1.0)** | 1.0 (1.0–1.0) | |
| ICPC code[c] N (%) | P98 Psychosis NOS/other | | 242 (2.0) | 5,082 (0.3) | 6.07 (5.32–6.92)** |
| | P71 Organic psychosis other | | 59 (0.5) | 6,858 (0.5) | 4.43 (3.41–5.75)** |
| | P99 Psychological disorders, other | | 566 (4.8) | 14,310 (1.0) | 3.83 (3.51–4.18)** |
| | P77 Suicide/suicide attempt | | 110 (0.9) | 3,318 (0.2) | 3.80 (3.14–4.60)** |
| | P72 Schizophrenia | | 158 (1.3) | 5,348 (0.4) | 3.36 (2.87–3.95)** |
| | P71–73 and/or P98 Psychosis, any form | | 500 (4.2) | 20,645 (1.4) | 4.37 (3.99–4.79)** |

MID: Mild intellectual disability; ID: Intellectual disability; MH: Mental health; ICPC: International Classification of Primary Care; **p < .001, MID compared with without-ID; apercentage of the total number of men/women within the group; bOR adjusted for age, sex, and years registered in the database; ooverview of the 5 ICPC codes of MH complaints/disorders with the highest odds and combined related codes

## Care provided

The GP had a median of 6.4 consultations per person per year in the MID group with an MH problem, compared to 4.0 consultations in the matched group without ID (Table 3.3). In the MID group as a whole, this was 4.3 consultations versus 2.3 in the group without ID (Supplementary Table 3.2). In all groups, women had more consultations. Slightly fewer people in the MID group with MH problems had an MHNP consultation (24.8 vs 26.7%; p<.001), and both the GP and the MHNP provided more short than long consultations and more home visits to people with both MID and MH problems, compared to the matched group without ID (Table 3.3).

The GP provided a median of 2.7 unique types of medication prescription categories per person per year in the MID group with an MH problem, compared to 2.0 prescriptions in the matched group without ID (Table 3.4). In the whole MID group, this was 2.0 prescriptions versus 1.0 in the group without ID (Supplementary Table 3.2). Of the MID group with an MH problem, 55.4% received at least one psychotropic prescription (OR 1.39, 95%CI 1.31–1.47), 19.9% an antipsychotic (N05A; OR 3.15, 95%CI 2.90–3.41), and 24.9% an anxiolytic (N05B; OR 1.41, 95%CI 1.32–1.51). In addition, 8.7% received an anti-epileptic prescription (N03A; OR 2.05, 95%CI 1.83–2.29).

**Table 3.3.** Consultations with general practitioners and mental health nurse practitioners

| | | MID-MH *N=5,808* | Match-MH[b] *N=32,232* | OR (95%CI)[c] |
|---|---|---|---|---|
| **GP consultations** | | | | |
| People with ≥1 consultation during research period, N (%) | Total | 5,702 (98.2) | 22,708 (97.7) | 1.29 (1.04–1.60)[**] |
| | Men[a] | 3,283 (97.3) | 13,070 (96.9) | 1.22 (0.97–1.54) |
| | Women[a] | 2,419 (99.3) | 9,638 (99.0) | 1.67 (0.98–2.83) |
| Median consultations per year (25–75 percentile) | Total | 6.4 (3.3–11.5)[**] | 4.0 (2.0–7.3) | |
| | Men | 5.0 (2.5–8.8)[**] | 3.3 (1.7–5.8) | |
| | Women | 9.0 (5.0–15.2)[**] | 5.5 (3.0–9.0) | |
| Type of consultation[x] | Total (N) | 141,267 | 357,841 | |
| | Short consultation, N (%) | 66,173 (46.8) | 163,943 (45.8) | 1.05 (1.03–1.06)[**] |
| | Long consultation, N (%) | 21,052 (14.9) | 60,504 (16.9) | 0.86 (0.85–0.88)[**] |
| | Home visit short, N (%) | 1,626 (1.2) | 2,002 (0.6) | 2.12 (1.98–2.26)[**] |
| | Home visit long, N (%) | 1,255 (0.9) | 2,571 (0.7) | 1.25 (1.16–1.33)[**] |
| | Consultation by phone, N (%) | 50,680 (35.9) | 125,560 (35.1) | 1.03 (1.02–1.05)[**] |
| | E-mail consultation, N (%) | 481 (0.3) | 3,261 (0.9) | 0.37 (0.34–0.41)[**] |

**Table 3.3.** Continued

| | | MID-MH N=5,808 | Match-MH[b] N=32,232 | OR (95%CI)[c] |
|---|---|---|---|---|
| **MHNP consultations** | | | | |
| People with ≥1 consultation during research period, N (%) | Total | 1,442 (24.8) | 6,195 (26.7) | 0.91 (0.85–0.98)* |
| | Men[a] | 710 (21.0) | 3,130 (23.2) | 0.89 (0.81–0.97)* |
| | Women[a] | 732 (30.1) | 3,065 (31.5) | 0.94 (0.85–1.04) |
| Median consultation per year (25–75 percentile) in people ≥1 consultation in research period | Total | 1.5 (0.8–3.3) | 1.3 (0.7–2.7) | |
| | Men | 1.3 (0.7–2.8) | 1.3 (0.7–2.4) | |
| | Women | 1.5 (0.8–4.0) | 1.5 (0.8–3.0) | |
| Type of consultation[d] | Total (N) | 11,249 | 36,125 | |
| | Short consultation, N (%) | 274 (2.4) | 564 (1.6) | 1.62 (1.40–1.88)** |
| | Long consultation, N (%) | 8,586 (76.3) | 30,711 (85.0) | 0.57 (0.54–0.60)** |
| | Short home visit short, N (%) | 15 (0.1) | 17 (0.0) | not applicable |
| | Long home visit, N (%) | 288 (2.6) | 204 (0.6) | 4.16 (3.46–5.00)** |
| | Consultation by phone, N (%) | 1,994 (17.7) | 3,949 (10.9) | 1.77 (1.67–1.88)** |
| | E-mail consultation, N (%) | 91 (0.8) | 572 (1.6) | 0.53 (0.42–0.66)** |
| | Group consultations, N (%) | <10[e] | 108 (0.3) | not applicable |

MID-MH: Group with mild intellectual disability and a mental health problem; Match-MH: Match control group with MH problem; GP = General practitioner; MHNP: Mental health nurse practitioner; **p < .001, *p < .05, MID compared with without-ID; [a]percentage of the total number of men/women within the group; [b]Match-MH: each individual from the MID-MH group randomly matched by age, sex, and number of years in the dataset to four individuals in the without-ID group; [c]OR calculated for variable with an absolute number of ≥ 30 people in one of the groups, adjusted for age, sex, and years registered in the database; [d]Long: >20 minutes, short: <20 minutes, percentage of total number of consultations; [e]Absolute numbers below 10 may are not displayed.

# Discussion

In this primary care database study, we found that almost half of the people with MID experienced MH problems versus one third of the people without ID, with large differences in substance abuse, suicide attempts, and psychosis. GPs provided more consultations and types of medication prescriptions to people with a combination of MID and an MH problem compared to matched people without ID or with MID alone. More than 80% of the persons with MID were not registered by the GP as such.

**Table 3.4.** Medication prescriptions

| | MID-MH<br>*N=5,808* | Match-MH<br>*N=23,232* | OR (95%CI)a |
|---|---|---|---|
| **All medication** | | | |
| ≥1 prescription during research period, N (%) | 5,450 (93.8) | 21,452 (92.3) | 1.31 (1.16–1.48)** |
| Median types prescriptions per year (25–75 percentile) | 2.7 (1.3–4.5)** | 2.0 (1.0–3.3) | |
| **Psychotropics** | | | |
| ≥1 prescription during research period, N (%) | 3,271 (55.4) | 11,072 (47.7) | 1.39 (1.31–1.47)** |
| Median types prescriptions per year in people ≥1 psychotropic prescription in research period (25–75 percentile) | 0.5 (0.3–1.0)** | 0.5 (0.3–1.0) | |
| N05A Antipsychotics, N (%) | 1,158 (19.9) | 1,716 (7.3) | 3.15 (2.90–3.41)** |
| N05B Anxiolytics, N (%) | 1,446 (24.9) | 4,473 (19.3) | 1.41 (1.32–1.51)** |
| N05C Hypnotics and sedatives, N (%) | 949 (16.3) | 3,603 (15.5) | 1.07 (0.99–1.16) |
| N06A Antidepressant, N (%) | 1,459 (25.1) | 5,096 (21.9) | 1.20 (1.12–1.29)** |
| N06B Psychostimulants, N (%) | 275 (4.7) | 1,177 (5.1) | 0.93 (0.81–1.07) |
| N06D Anti-dementia drugs, N (%) | <10[b] | 23 (0.1) | not applicable |
| N07B Drugs used in addictive disorders, N (%) | 385 (6.6) | 1,150 (5.0) | 1.38 (1.22–1.55)** |
| **Anti-epileptics** | | | |
| ≥1 anti-epileptic N03A prescription during research period, N (%) | 504 (8.7) | 1,048 (4.5) | 2.05 (1.83–2.29)** |

MID-MH: Group with mild intellectual disability and a mental health problem; Match-MH: Match control group with MH problem;
**p < .001, MID compared with without-ID; [a]OR calculated for variable with an absolute number of ≥ 30 people in one of the groups, adjusted for age, sex, and years registered in the database; [b]Absolute numbers below 10 may are not displayed.

## Strengths and limitations

An important strength of this study is the unique focus on people with *mild* intellectual disabilities. By linking a primary care database with a social services information database, we identified people with MID in primary care. This fills a blind spot about people with MID who would have been overlooked without data linkage. Another important strength is that this study does not focus only on MH disorders, but gives a broader view by including MH complaints.

There are some limitations regarding the use of databases containing routinely collected (health) data. In the NIVEL-PCD, details of diagnoses and treatments were limited, and the care provided could not be linked to specific ICPC-P codes. The SN-MID database is composed mostly of users of work-related social services, resulting in an underrepresentation of older people. Finally, the database contains no exact information on intellectual and adaptive functioning on an individual level, so it cannot be ruled out that some people with more severe ID or borderline intelligence were included in our MID group. However, the SN-MID database is currently the most complete method available in the Netherlands to identify people with MID.

### Comparison with existing literature

In our study, 25.3% of the people with MID had an MH disorder. This is comparable to Sheehan et al.'s primary care cohort study,[2] which found a point prevalence of 21% in people with any form of ID. Our incorporation of MH complaints has not been studied before in primary care.

The high prevalence of psychosis in MID (4.2%) we found was also observed in other primary care studies.[5, 17] We found a higher prevalence of substance abuse in people with MID compared to people without ID. A systematic review, that did not include primary care settings, concluded that people with MID are at high risk of developing substance use disorder.[18] The striking relatively high prevalence of 'suicide/suicide attempt' (P77) and unspecified ICPC-P codes (P29, P99) has not been previously reported in primary care studies. However, Dodd et al.'s systematic review of suicidality in people with ID revealed that the presence of having an MH disorder is seen as an important risk factor for suicide in these patients.[19] More importantly, it shows a lack of well-designed studies on suicide in people with ID, and there are limited ID-specific assessments or therapeutic interventions for suicidality.

The absence of a P85 code for the vast majority of people with MID is in line with previous research.[10] The relatively high prevalence of the ICPC codes 'limited function/disability' (P28) and 'specific learning problems' (P24) in people with MID in this study could indicate that these codes are used as a substitute for P85.

The higher number of GP consultations, home visits, and telephone consultations for people with MID and MH problems is in line with earlier research on people with ID in general in primary care.[17, 20, 21] The relatively high number of medication prescriptions, especially psychotropics, for people with MID is consistent with earlier primary care research concerning people with ID.[2, 20, 22] From earlier research it is known that people with ID have greater healthcare needs with higher levels of morbidity and premature mortality than patients without ID, a situation to which insufficient quality of healthcare is a substantial contributor.[23] Therefore, the differences that we found in the prevalence of MH problems and provided care between patients with MID and without ID can be an indication of extra healthcare needs in this specific patient group. However, a recent review by us on primary MH care to people with ID revealed that current primary MH care to this patient group is of an insufficient standard, in terms of underdiagnosis of MH disorders, overmedication, and lack of effective patient follow-up, as well as limited GP experience in managing these patients.[9] A possible reflection of the reported difficulties in providing adequate MH care to these patients may be an additional contributing factor to the differences observed.

### Implications for research and practice

Timely recognition and treatment of not only MH disorders but also MH complaints are important for the physical and emotional wellbeing, and thus for the quality of life, of people with MID and therefore needs to be prioritised.[24] This requires GPs to be aware of the high prevalence of MH problems in people with MID and to be aware and knowledgeable about the effect of MID on symptom presentation, communication, and treatment. The results of this study give rise to several opportunities to improve the quality of primary MH care for people with MID.

Firstly, the relatively high use of unspecified ICPC-P codes (P29, P99) and the relatively high number of people with MID who received psychotropic prescriptions could be signs that GPs experience difficulties in classifying and treating MH problems in people with MID. Communication difficulties, an atypical presentation of MH symptoms, and diagnostic masking or overshadowing, where symptoms are obscured by the ID or mislabelled, can contribute to these difficulties.[25] Therefore, research on applicable primary MH guidelines for this patient group is important.

Secondly, it is highly recommended to invest in recurring specific (postgraduate) training programmes for GPs. The relatively high prevalence of substance abuse and suicide in our study suggests that a proactive and preventive approach, aimed at identifying risk factors for MH problems and providing health education, should be part of this education.

Thirdly, GPs should be aware of the importance of identifying and registering MID, both for good care provision and for research purposes. ID screening tools can be helpful for identifying MID and have been developed for GP practice, but further implementation is needed. [26, 27] Clear agreement should be reached by GPs about when and how MID is recorded.

Fourthly, it is important that primary care is accessible for people with MID and that their (mental) health needs are met. Future research should address the nature of the identified high care utilisation in more detail. Our findings may be seen as a sign of additional healthcare needs and more intensive GP care provided to this patient group, putting a relatively high demand on primary care practices. As previous research indicated, GPs do not feel confident about providing care to people with ID, [28] particularly to those with additional MH problems. [9, 11] Support for GPs may help them better address these complex health needs and may improve the care that they provide. According to patients with ID, adaptations in how care is provided could be helpful, such as improving GPs' communication skills, extra consultation time, continuity of care from the same GP, and involvement of family or carers in consultations and in information provision. [29, 30] Periodic health assessments, supported by an instrument, are seen as another way to identify (mental) health needs. [31] Finally, although our database contained no information on referrals and consultations, it is important for GPs to look to care professionals in their direct network for collaboration and support. Effective collaboration, in specific, is regarded as beneficial for the outcome of mental healthcare in primary care. [32] Therefore it is important to learn from best practices [32-34] and invest in (local) integrative and collaborative primary MH care models.

It remains of utmost importance to actively engage both GPs and patients with MID in the development of the suggested improvement strategies to ensure that they meet their needs and are applicable and feasible in daily practice.

## Conclusion

We found that MID is most often not registered by GPs and most likely partially unrecognised. Almost half of the people with MID visited the GP with an MH problem and were provided with more care in terms of consultations and types of prescribed medication categories compared to people without ID or with MID alone. This may be an indication that people with both MID and MH problems have even higher health care needs than people with MID alone with a corresponding higher demand in primary care. In addition, our results suggest that GPs struggle to register the MID as such, to establish the correct MH diagnosis and, consequently, to provide appropriate treatment. These findings illustrate the relevance of improving the quality of primary MH care for people with MID. This may be achieved by creating more GP awareness and knowledge of MH problems in people with MID, the importance of MID recognition, additional (care) needs, and the need for collaboration with relevant local care professionals.

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# Supplementary

**Supplementary Table 3.1.** Period prevalence of mental health problems

| | | | MID | Without ID | OR (95%CI)c |
|---|---|---|---|---|---|
| Patients, N | | Total | 11,887 | 1,464,196 | |
| | | Men | 7,338 | 714,136 | |
| | | Women | 4,549 | 750,060 | |
| **MH problems (P1–P99)** | | | | | |
| ≥1 MH problem | N (%) | Total | 5,808 (48.9) | 444,520 (30.4) | 2.50 (2.41–2.59)** |
| | | Men[a] | 3,373 (46.0) | 186,985 (26.2) | 2.55 (2.43–2.67)** |
| | | Women[a] | 2,435 (53.5) | 257,535 (34.3) | 2.43 (2.29–2.58)** |
| | Age M(SD) | | 37.1 (14.3)** | 50.6 (18.4) | |
| | Age group, N (%[b]) | 18–24 | 1,600 (48.8) | 36,344 (27.2) | 2.75 (2.56–2.95)** |
| | | 25–34 | 1,391 (51.4) | 66,434 (29.1) | 2.74 (2.54–2.96)** |
| | | 35–44 | 881 (52.7) | 72,351 (30.7) | 2.67 (2.42–2.94)** |
| | | 45–54 | 1,052 (48.9) | 88,513 (30.5) | 2.38 (2.18–2.59)** |
| | | 55–64 | 697 (44.8) | 74,458 (29.7) | 2.04 (1.84–2.26)** |
| | | 65–74 | 179 (36.7) | 51,500 (26.9) | 1.77 (1.47–2.13)** |
| | | >75 | <10[d] | 54,920 (40.9) | not applicable |
| | Median number of unique MH problems (25–75 percentile) | | 2.0 (1.0–3.0)** | 1.0 (1.0–3.0) | |
| **MH complaint (ICPC P1–P29)** | | | | | |
| ≥1 MH complaint | N (%) | Total | 4,299 (36.2) | 313,200 (21.4) | 2.39 (2.30–2.49)* |
| | | Men[a] | 2,541 (34.6) | 136,786 (19.2) | 2.40 (2.29–2.52)* |
| | | Women[a] | 1,758 (38.6) | 176,414 (23.5) | 2.37 (2.23–2.52)* |
| | Median number of unique MH complaints (25–75 percentile) | | 1.0 (1.0–2.0)** | 1.0 (1.0–1.0) | |

**Supplementary Table 3.1.** continued

| | | MID | Without ID | OR (95%CI)c |
|---|---|---|---|---|
| ICPC code N (%) | P01 Feeling anxious/nervous/tense | 573 (4.8) | 50,158 (3.4) | 1.61 (1.48–1.76)** |
| | P02 Acute stress reaction | 648 (5.5) | 36,848 (2.5) | 2.16 (1.99–2.34)** |
| | P03 Feeling depressed | 372 (3.1) | 35,104 (2.4) | 1.31 (1.18–1.46)** |
| | P04 Feeling/behaving irritably/angry | 224 (1.9) | 7,809 (0.5) | 3.47 (3.03–3.97)** |
| | P05 Senility, feeling/behaving old | <10[d] | 3,759 (0.3) | not applicable |
| | P06 Sleep disturbance | 829 (7.0) | 84,341 (5.8) | 1.72 (1.60–1.85)** |
| | P07 Sexual desire reduced | 16 (0.1) | 1,849 (0.1) | not applicable |
| | P08 Sexual fulfilment reduced | 56 (0.5) | 4,543 (0.3) | 1.40 (1.08–1.83)* |
| | P09 Sexual preference concern | 21 (0.2) | 597 (0.0) | not applicable |
| | P10 Stammering/stuttering/tic | 21 (0.2) | 552 (0.0) | not applicable |
| | P11 Eating problem in child | <10 | 123 (0.0) | not applicable |
| | P12 Bedwetting/enuresis | 27 (0.2) | 434 (0.0) | not applicable |
| | P13 Encopresis/bowel training problem | <10[d] | 50 (0.0) | not applicable |
| | P15 Chronic alcohol abuse | 364 (3.1) | 15,062 (1.0) | 3.12 (2.80–3.47)** |
| | P16 Acute alcohol abuse | 81 (0.7) | 2,489 (0.2) | 3.03 (2.43–3.79)** |
| | P17 Tobacco abuse | 799 (6.7) | 49,034 (3.3) | 2.09 (1.95–2.25)** |
| | P18 Medication abuse | 101 (0.8) | 5,967 (0.4) | 3.44 (2.82–4.20)** |
| | P19 Drug abuse | 407 (3.4) | 9,233 (0.6) | 3.23 (2.91–3.57)** |
| | P20 Memory disturbance | 140 (1.2) | 28,352 (1.9) | 1.59 (1.34–1.88)** |
| | P21 Overactive/hyperkinetic syndrome | 367 (3.1) | 12,463 (0.9) | 2.09 (1.88–2.33)** |
| | P22 Child behaviour symptom/complaint | 99 (0.8) | 9,408 (0.6) | 1.33 (1.09–1.62)* |
| | P23 Adolescent behaviour symptom/complaint | 96 (0.8) | 2,362 (0.2) | 3.51 (2.86–4.32)** |
| | P24 Specific learning problem | 116 (1.0) | 1,424 (0.1) | 6.23 (5.14–7.55)** |
| | P25 Phase of life problem adult | 16 (0.1) | 4,137 (0.3) | not applicable |
| | P27 Fear of mental disorder | <10[d] | 822 (0.1) | not applicable |
| | P28 Limited function/disability | 303 (2.5) | 1,018 (0.1) | 38.18 (33.34–43.72)** |
| | P29 Psychological symptom/complaints other | 459 (3.9) | 25,528 (1.7) | 2.07 (1.89–2.28)** |
| | P15–19 Substance abuse, any form | 1,549 (13.0) | 76,177 (5.2) | 2.64 (2.50–2.79)** |

**Supplementary Table 3.1.** continued

| | | | MID | Without ID | OR (95%CI)c |
|---|---|---|---|---|---|
| **MH disorders (ICPC P70-P99)** | | | | | |
| ≥1 MH disorders | N (%) | Total | 3,006 (25.3) | 220,298 (15.0) | 2.09 (2.00–2.18) |
| | | Men[a] | 1,646 (22.4) | 84,198 (11.8) | 2.22 (2.10–2.35) |
| | | Women[a] | 1,360 (29.9) | 136,100 (18.1) | 1.92 (1.82–2.07) |
| | Median number of unique MH disorders (25–75 percentile) | | 1.0 (1.0–1.0)** | 1.0 (1.0–10) | |
| ICPC code, N (%) | P70 Dementia | | 24 (0.2) | 15,512 (1.1) | not applicable |
| | P71 Organic psychosis other | | 59 (0.5) | 6,858 (0.5) | 4.43 (3.41–5.75)** |
| | P72 Schizophrenia | | 158 (1.3) | 5,348 (0.4) | 3.36 (2.87–3.95)** |
| | P73 Affective psychosis | | 87 (0.7) | 5,005 (0.3) | 2.49 (2.01–3.09)** |
| | P74 Anxiety disorder/anxiety state | | 706 (5.9) | 54,668 (3.7) | 1.59 (1.48–1.72)** |
| | P75 Somatization disorder | | 63 (0.5) | 4,004 (0.3) | 1.89 (1.47–2.43)** |
| | P76 Depressive disorder | | 801 (6.7) | 76,663 (5.2) | 1.46 (1.36–1.58)** |
| | P77 Suicide/suicide attempt | | 110 (0.9) | 3,318 (0.2) | 3.80 (3.14–4.60)** |
| | P78 Neuraesthenia/surmenage | | 371 (3.1) | 47,088 (3.2) | 0.90 (0.82–1.00) |
| | P79 Phobia/compulsive disorder | | 86 (0.7) | 6,010 (0.4) | 1.56 (1.26–1.94)** |
| | P80 Personality disorder | | 506 (4.3) | 22,623 (1.5) | 2.31 (2.11–2.53)** |
| | P98 Psychosis NOS/other | | 242 (2.0) | 5,082 (0.3) | 6.07 (5.32–6.92)** |
| | P99 Psychological disorders, other | | 566 (4.8) | 14,310 (1.0) | 3.83 (3.51–4.18)** |
| | P71–73 and/or P98 Psychosis, any form | | 500 (4.2) | 20,645 (1.4) | 4.37 (3.99–4.79)** |

MID: Mild intellectual disability; ID: Intellectual disability; MH: Mental health; ICPC: International Classification of Primary Care;**p < .001 and *p < .05 MID compared with without-ID; [a]percentage of the total number of men/women within the group; [b]percentage of the total number of persons in the age group within the group; [c]OR calculated for variable with an absolute number of ≥ 30 people in one of the groups, adjusted for age, sex, and years registered in the database; Absolute numbers below 10 are not displayed.

**Supplementary Table 3.2.** Consultations and medication prescriptions

| | | MID N=11,887 | Match without ID N=47,548 | OR (95%CI)[b] |
|---|---|---|---|---|
| **GP consultations** | | | | |
| People with ≥1 consultation during research period, N (%) | Total | 10,967 (92.3) | 41,999 (88.3) | 1.66 (1.54–1.78)** |
| | Men[a] | 6,575 (89.6) | 25,006 (85.2) | 1.56 (1.44–1.70)** |
| | Women[a] | 4,392 (96.5) | 16,993 (93.3) | 2.06 (1.73–2.44)** |
| Median number of consultations per registered year (25–75 percentile) | Total | 4.3 (1.7–8.7)** | 2.3 (1.0–4.8) | |
| | Men | 3.0 (1.0–6.5) | 1.8 (0.6–3.6) | |
| | Women | 6.7 (3.3–12.0) | 3.5 (1.6–6.3) | |
| Type of consultation[c] | Total (N) | 206,381 | 457,777 | |
| | Short consultation, N (%) | 102,758 (49.8) | 231,456 (50.6) | 0.94 (0.94–0.95)** |
| | Long consultations, N (%) | 28,451 (13.8) | 66,544 (14.5) | 0.91 (0.90–0.93)** |
| | Home visit short, N (%) | 2,315 (1.1) | 2,890 (0.6) | 2.16 (2.08–2.26)** |
| | Home visit long, N (%) | 1,830 (0.9) | 3,070 (0.7) | 1.47 (1.40–1.54)** |
| | Consultations by phone, N (%) | 70,349 (34.1) | 150,016 (32.8) | 1.07 (1.06–1.08)** |
| | E-mail consultations, N (%) | 678 (0.3) | 3,801 (0.8) | 0.38 (0.35–0.41)** |
| **Total prescriptions of medication** | | | | |
| People with ≥1 prescription during research period, N (%) | | 10,362 (87.2) | 38,271 (80.5) | 1.76 (1.66–1.87)** |
| Median type prescriptions per year (25–75 percentile) | | 2.0 (0.8–3.8)** | 1.0 (0.3–2.5) | |

MID: Group with mild intellectual disability; Match without-ID: Match control group without intellectual disability; GP: General practitioner; **p < .001 MID compared with without-ID; [a]percentage of the total number of men/women in the group; [b]OR calculated for variable with an absolute number of ≥ 30 people in one of the groups, adjusted for age, sex, and years registered in the database; [c]Long: >20 minutes, short: <20minutes, percentage of total number of consultations

# Chapter 4

# Mental healthcare for adults with mild intellectual disabilities: a population-based database study in Dutch mental health services

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# Abstract

**Background:** Adults with mild intellectual disabilities (MID) experience more mental health (MH) disorders compared to the general population. However, MH care may be insufficiently tailored to match their needs. Detailed information is lacking regarding care provided to people with MID in MH services.

**Aim**: To compare MH disorders and care provided to patients with and without MID in Dutch MH services, including those patients whose MID status was missing in MH service files.

**Method:** In this population-based database study, we used a Statistics Netherlands MH service database, containing health insurance claims of patients who utilised advanced MH services between 2015 and 2017. Patients with MID were identified by linking this database with Statistic Netherlands' social services and long-term care databases.

**Results:** We identified 7,596 patients with MID, of whom 60.6% had no ID registration in the MH service files. Compared to patients without ID (n=329,864), they had different profiles of MH disorders. They received diagnostic (OR 0.71, 95%CI 0.67–0.75) and treatment activities (OR 0.56, 95%CI 0.53–0.59) less often and required more interprofessional consultations outside the MH service (OR 2.06, 95%CI 1.97–2.16), more crisis interventions (OR 2.00, 95%CI 1.90–2.10), and more MH hospital admissions (OR 1.72 95%CI 1.63–1.82).

**Conclusions:** Patients with MID in MH services have different profiles of MH disorders and care compared to patients without ID. In particular, fewer diagnostics and treatments are provided, more so in those with no ID registered and potentially unknown, putting patients with MID at risk of undertreatment and poorer MH outcomes.

# Introduction

Up to a third of adults with mild intellectual disabilities (MID), characterised by a significant deficit in intellectual (IQ range 50–70) and adaptive functioning, [1] experience mental health (MH) disorders. This is double the general population estimates. [2] The combination of MID and MH disorders results in poorer general health outcomes, such as more all-cause hospital admissions and emergency department visits, compared to MID or MH disorders alone. [3, 4] A lack of high-quality research on appropriate (MH) care for this specific patient group contributes to this health disparity. [5]

There are several reasons for concern regarding the quality of care for patients with a combination of MID and MH disorders in MH services. Firstly, either the MID or the MH disorder may often be missed when symptoms are attributed exclusively to either of these specific disorders, though both states are present, so-called diagnostic overshadowing. [6, 7] Secondly, MH service professionals perceive a lack of knowledge and experience in treating patients with a combination of MID and MH disorders. [8, 9] Thirdly, there is little research on how MH care should be organised and provided to people with MID.[5] In MH services, patients with intellectual disabilities (ID) may be excluded from certain treatments or even any care at all, because the organisation lacks knowledge and expertise. [4, 8] Consequently, patients with ID experience long waiting times because of the scarcity of MH services specialised in patients with ID. [4] Fourthly, patients with MID report negative experiences with MH services, including poor accessibility and information provision. [5, 10] Finally, detailed information is lacking regarding the characteristics of MH disorders and care provided to people with MID in MH services. This also applies to those patients whose MID is potentially missed and whose specific needs are thus a blind spot for the MH service professionals. Such information can give guidance to improve MH care for people with MID and future research. We therefore conducted a population-based database study on the prevalence of a wide range of MH disorders and MH care provided to people with and without MID in MH services, including those patients whose MID is not recorded in MH service files.

# Method

## Study design and data source

This population-based database study investigated the prevalence of a range of MH disorders and care provided to all patients utilising advanced MH services in the Netherlands between 1 January 2015 and 31 December 2017. Information was retrieved from health insurance claims, which are collected in a central database at Statistics Netherlands (SN), the Dutch national statistics office.[11] In the Netherlands, MH services are subdivided into basic MH services, for mild and low-complex MH problems, and advanced MH services, for more severe and complex MH disorders.[12] Both types of MH services are accessible to all patients after assignment and referral by a general practitioner, and all costs involved are covered by mandatory health insurance. Health insurance claims submitted by MH care providers are collected and processed in a standardised manner and available at SN for research purposes in the SN-MH service database. This study focused on patients with more severe and complex MH disorders in advanced MH services, which for the sake of readability are called MH services in the rest of this article.

In the MH service files, an ID can be reported as a contributing diagnosis. To take potential under-recognition and underreporting of MID in MH services into account,[7] the MH service database was linked to a combined social services and long-term care database that included all users (in 2015) of services under the Chronic Care Act, the Disability Benefit Act, or the Sheltered Employment Act and for whom MID was indicated as the reason for calling upon any of these services. This is the largest available national dataset on Dutch individuals with MID based on SN research commissioned by the Ministry of Health.[13] This linkage allowed the generation of two MID subgroups: one with and one without an ID registration in the original MH service database (Figure 1). The comparison group (no ID) consisted of all other MH patients without an (M)ID registration in any of the databases used. We included persons aged 18 years or older in 2015 who were available for at least one year follow-up and completed their trajectory before 31 December 2017. Patients aged 75 years and older were excluded because of a low prevalence of MID in the study registries and thus limited possibility for comparing these age groups.

This study used pseudonymised non-public microdata, which under certain conditions are accessible for statistical and scientific research from Statistics Netherlands.[11] The study protocol was reviewed by the Radboud university medical center institutional Ethics Committee, who passed a positive judgment (2017-3921). Results are reported in accordance with the RECORD statement.[14]

### Outcomes

The primary outcomes of this study consist of the prevalence of a range of MH disorders and characteristics of MH care provided. Reported primary diagnoses, based on DSM-IV (*Diagnostic and Statistical Manual of Mental Disorders*, 4th edition), were taken from the submitted insurance claims in the SN-MH service database and converted by SN into one of 16 pre-defined diagnostic groups (Supplementary table). Reported contributing diagnoses were searched to determine the presence of an ID in the original MH service files.

An MH trajectory, defined as the period in which a patient receives MH care for a specific diagnosis, was initiated for each primary diagnosis. The MH trajectories include information on the specific setting in which care was provided, the start and end dates of the trajectory, and the care activities within the trajectory. We used this information to calculate the duration of MH trajectories and counted the frequency of various care activities. The duration of trajectories and the number of care activities provide an impression of the intensity and nature of care provided in MH services. The MH care setting (generic long- or short-term care, eldercare, addiction care, or forensic care) provides information on the type of care settings in which patients with MID are most likely to receive care. Care activities were segregated into those with direct and those with indirect patient involvement. Direct patient care included diagnostic, treatment, or guidance activities. Regarding treatment activities, therapeutic interventions like psychotherapy or pharmacotherapy were listed separately, as they are important treatment models in MH care and often topics of discussion concerning their applicability in patients with MID. [5] Indirect patient care consisted of coordination of care, time consumed by no-shows, interprofessional consultations in and outside the MH service setting, and legal proceedings activities. Indirect patient care was included as an outcome of this study on the assumption from clinical experience [KP, MM, JW] that indirect patient care accounts for a larger proportion of the total care provided to patients with MID than to other MH patients. In addition, interprofessional collaboration, reflected in interprofessional consultations, is considered a way to improve MH outcomes in patients with ID. [15, 16] Finally, crisis interventions and hospital admissions were included, as they have been used in previous research to express (mental) health differences between groups. [3]

## Statistical analysis

Variables for all groups were calculated as frequencies, in percentages, or means with standard deviation. The mean duration of MH trajectories was calculated as the mean of all trajectories per study group. Comparisons were made between the MID group and the no-ID group, and between the MID subgroup without ID registration in the MH service database and the no-ID group. Differences between these groups were tested for statistical significance by chi-square tests for categorical variables and T-tests. The relation between MID and outcomes in MH services was analysed by logistic regression modelling, controlling for age and sex, and presented by odds ratios (OR) with 95% confidence intervals (95%CI). P-values <.05 were considered statistically significant. Analyses were conducted in SPSS, version 25.0.

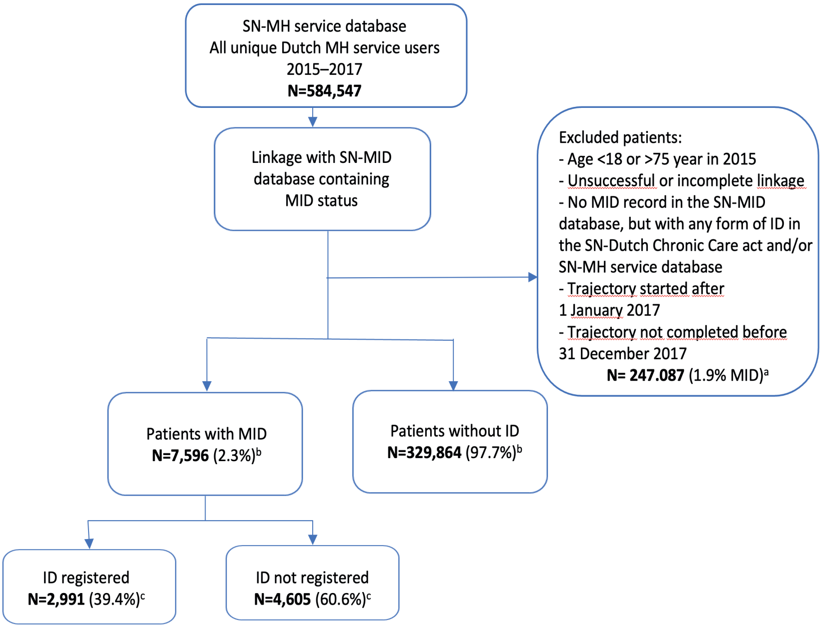

**Figure 4.1** Flowchart of study sample selection

SN-MH service database: Statistical Netherlands Mental Health service database; SN-MID database: Statistical Netherlands Mild Intellectual Disability database; MH: mental health; MID: mild intellectual disability; ID: intellectual disability; [a] Percentage of excluded patients with an MID record in the SN-MID database; [b] Percentage of included patients with an MID; [c] Percentage of MID patients with or without ID registration in SN-MH service database.

# Results

In the MH service database, data were available for 337,460 eligible patients, of whom 7,596 were identified with an MID. These patients were more often male (57.5 vs 46.2%) and younger (32.5 vs 40.5 years) as compared to patients without ID (N=329,864). In total, 60.6% of the patients with an MID (N=4,605) had no record of an ID status in the MH service database (Table 4.1).

**Table 4.1.** Demographics of groups

| | | No ID | MID | MID No ID registration |
|---|---|---|---|---|
| Total N | | 329,864 | 7,596 | 4,605 |
| Men, N (%) | | 152,305 (46.2) | 4,371 (57.5)*[a] | 2,616 (56.8)*[a] |
| Age, M (SD) | | 40.5 (14.4) | 32.5 (12.8)* | 32.6 (13.0)* |
| Age groups, N (%) | 18–24 | 52,246 (15.8) | 2,968 (39.1)**[b] | 1,853 (40.2)**[b] |
| | 25–49 | 183,764 (55.7) | 3,560 (46.9) | 2,077 (45.1) |
| | 50–74 | 93,854 (28.5) | 1,068 (14.1) | 675 (14.7) |

MID: mild intellectual disability; ID: intellectual disability; *p<.001; **p<.001 for age group distribution a MID/MID no ID registartion compared with no ID; b Age group distribution MID/ MID no ID registartion compared with no ID

Eight of the 16 pre-defined diagnostic groups were significantly more prevalent in patients with MID (Table 4.2), with the highest OR for 'Schizophrenia and other psychotic disorders' (OR 2.06, 95%CI 1.90–2.22) and 'Other childhood disorders' (OR 2.77, 95%CI 2.02–3.81). Seven diagnostic groups were less prevalent in patients with MID, with low ORs for 'Depressive disorders' (OR 0.46, 95%CI 0.43–0.50) and 'Personality disorders' (OR 0.41, 95%CI 0.37–0.45). In the MID subgroup without ID registration, in particular more patients had a 'No or an unknown diagnosis' as compared to patients without ID (OR 2.67, 95%CI 2.50–2.84).

**Table 4.2.** Period prevalence of mental health disorders

| | No ID N=329,864 | MID N=7,596 | OR (CI95%)[a] | MID No ID registration N=4,605 | OR (CI95%)[b] |
|---|---|---|---|---|---|
| Other childhood disorders N (%) | 441 (0.1) | 43 (0.6) | 2.77 (2.02–3.81)** | 17 (0.4) | 1.85 (1.13-3.00)* |
| Schizophrenia and other psychotic disorders N (%) | 17,179 (5.2) | 827 (10.9) | 2.06 (1.90–2.22)** | 361 (7.8) | 1.56 (1.39-1.74)** |
| Other diagnosis N (%) | 12,615 (3.8) | 605 (8.0) | 1.82 (1.67–1.98)** | 298 (6.5) | 1.49 (1.32-1.68)** |
| No or unknown diagnosis N (%) | 85,821 (26.0) | 2,841 (37.4) | 1.78 (1.71–1.90)** | 1,958 (42.5) | 2.67 (2.50-2.84)** |
| Pervasive development disorders N (%) | 10,010 (3.0) | 573 (7.5) | 1.77 (1.62–1.94)** | 257 (5.6) | 1.30 (0.15–1.48)** |
| Neurocognitive disorders N (%) | 6,599 (2.0) | 101 (1.3) | 1.67 (1.36–2.06)** | 69 (1.5) | 1.84 (1.43–2.37)** |

**Table 4.2.** continued

| | No ID N=329,864 | MID N=7,596 | OR (CI95%)[a] | MID No ID registration N=4,605 | OR (CI95%)[b] |
|---|---|---|---|---|---|
| Other substance-related disorders N (%) | 16,516 (5.0) | 750 (9.9) | 1.40 (1.30–1.52)** | 408 (8.9) | 1.31 (1.18–1.46)** |
| Alcohol-related disorders N (%) | 17,861 (5.4) | 441 (5.8) | 1.13 (1.03–1.25)* | 220 (4.8) | 0.96 (0.84–1.11) |
| Anxiety disorders N (%) | 60,356 (18.3) | 1,242 (16.4) | 0.85 (0.79–0.90)** | 696 (15.1) | 0.77 (0.71–0.83)** |
| Bipolar and related mood disorders N (%) | 11,167 (3.4) | 163 (2.1) | 0.73 (0.63–0.86)** | 62 (1.3) | 0.49 (0.38–0.63)** |
| Attention deficit and conduct disorders N (%) | 16,885 (5.1) | 320 (4.2) | 0.55 (0.49–0.62)** | 160 (3.5) | 0.44 (0.38–0.52)** |
| Depressive disorders N (%) | 74,672 (22.6) | 811 (10.7) | 0.46 (0.43–0.50)** | 443 (9.6) | 0.42 (0.38–0.46)** |
| Feeding and eating disorders N (%) | 5,442 (1.6) | 70 (0.9) | 0.45 (0.36–0.57)** | 49 (1.1) | 0.52 (0.39–0.69)** |
| Personality disorders N (%) | 45,195 (13.7) | 541 (7.1) | 0.41 (0.37–0.45)** | 327 (7.1) | 0.43 (0.38–0.48)** |
| Somatic symptom disorders N (%) | 14,405 (4.4) | 115 (1.5) | 0.39 (0.32–0.47)** | 85 (1.8) | 0.47 (0.38–0.58)** |
| Other problems that are a reason for concern N (%) | 383 (0.1) | <10 | | <10 | |

MID: mild intellectual disability; ID: intellectual disability; OR: odds ratio; **P<.001; *P<.05; [a] MID vs no ID; [b] MID without ID registration compared with no ID

In table 4.3, we present an overview of the care provided. Patients with MID were provided with significantly shorter MH trajectories than patients without ID (286.8 vs 325.7 days). Trajectories were particularly short for patients in the MID subgroup without ID registration (252.9 days). Compared to patients without ID, patients with MID were more likely to receive care in an addiction or a forensic setting (OR 1.19, 95%CI 1.11–1.27 and 1.81, 95%CI 1.62–2.03, respectively) and less likely in a generic short-term setting (OR 0.76, 95%CI 0.72–0.80). Significantly fewer patients with MID than without ID were provided diagnostic (74.9 vs 79.7%) and treatment activities (67.7 vs 78.0%); in particular, fewer patients were provided psychotherapy (13.5 vs 31.0%). In addition, if psychotherapy was started, the mean number of psychotherapy activities per patient with MID was significantly lower (11.8 vs 19.3 activities per patient). The differences compared to the no-ID group were all more prominent in the MID subgroup without ID registration, with even fewer diagnostic (73.7%), treatment (59.9%), and/or psychotherapy (12.7%) activities.

Patients with MID more often had activities recorded without direct patient involvement, in particular interprofessional consultations outside the MH service setting (59.1 vs 42.1%) and activities concerning legal affairs (6.9 vs 3.8%), compared to patients with no ID. In addition, when internal or external interprofessional consultation was required within an MH trajectory, the mean number of consultations per patient with MID was higher (respectively, 134.9 vs 115.1 internal and 9.5 vs 6.2 external interprofessional consultations per patient).

Patients with MID were more likely to require a crisis intervention or an MH hospital admission compared to patients without ID (respectively, OR 2.00, 95%CI 1.90–2.10 and 1.72, 95%CI 1.63–1.82), including those patients where the ID was unregistered (respectively, OR 1.93, 95%CI 1.81–2.05 and 1.20, 95%CI 1.10–1.30).

**Table 4.3.** Care provided

| | | No ID N=329,864 | MID N=7,596 | OR (CI 95%)[a] | MID No ID registration N=4,605 | OR (CI 95%)[b] |
|---|---|---|---|---|---|---|
| **MH trajectory** | | | | | | |
| Cumulative durations of MH trajectories per patient in days, Mean (SD) | | 325.7 (236.9) | 286.8 (236.5)$^{**}$ | | 252.9 (218.4)$^{**}$ | |
| **Treatment setting** | | | | | | |
| Adult care long, N (%) | | 95,428 (28.9) | 2,370 (31.2) | 1.03 (0.98–1.09) | 1,215 (26.4) | 0.84 (0.79–0.90)$^{**}$ |
| Adult care short, N (%) | | 210,444 (63.8) | 4,713 (62.0) | 0.76 (0.72–0.80)$^{**}$ | 3,022 (65.6) | 0.95 (0.90–1.02) |
| Eldercare, N (%) | | 19,171 (5.8) | 124 (1.6) | 1.09 (0.88–1.35) | 91 (2.0) | 1.30 (1.00–1.68) |
| Addiction care, N (%) | | 30,123 (9.1) | 974 (12.8) | 1.19 (1.11–1.27)$^{**}$ | 545 (11.8) | 1.13 (1.03–1.24)$^{*}$ |
| Forensic, N (%) | | 6,520 (2.0) | 359 (4.7) | 1.81 (1.62–2.03)$^{**}$ | 169 (6.4) | 1.50(1.28–1.75)$^{**}$ |
| **Direct patient care** | | | | | | |
| Diagnostic activities, N (%) | | 262,445 (79.7) | 5,684 (74.9) | 0.71 (0.67–0.75)$^{**}$ | 3,387 (73.7) | 0.66 (0.62–0.71)$^{**}$ |
| Treatment activities, N (%) | | 256,910 (78.0) | 5,135 (67.7) | 0.56 (0.53–0.59)$^{**}$ | 2,751 (59.9) | 0.40(0.37–0.42)$^{**}$ |
| Psychotherapy activities | N (%) | 101,918 (31.0) | 1,024 (13.5) | 0.33 (0.30–0.35)$^{**}$ | 585 (12.7) | 0.30 (0.28–0.33)$^{**}$ |
| | Mean number per person (SD) | 19.3 (40.3) | 11.8 (22.5)$^{**}$ | | 12.3 (20.7)$^{**}$ | |
| Pharmacotherapy activities, N (%) | | 112,981 (34.3) | 2,371 (31.3) | 0.88 (0.84–0.92)$^{**}$ | 1,238 (26.9) | 0.71 (0.67–0.76)$^{**}$ |
| Supportive care activities, N (%) | | 24,213 (7.4) | 588 (7.8) | 1.10 (1.00–1.19)$^{*}$ | 317 (6.9) | 0.96 (0.86–1.08) |
| **Indirect patient care** | | | | | | |
| Coordination of care activity | N (%) | 188,983 (64.1) | 5,268 (73.4) | 1.58 (1.51–1.66)$^{**}$ | 2,907 (68,0) | 1.20 (1.13–1.27)$^{**}$ |
| | Mean number per person (SD) | 17.0 (50.1) | 21.1 (60.2)$^{**}$ | | 17.5 (57.2) | |
| Interprofessional consultation activity, internal | N (%) | 277,695 (94.1) | 6,867 (95.7) | 1.61 (1.49–1.74)$^{**}$ | 4,035 (94.4) | 1.21 (1.11–1.32)$^{**}$ |
| | Mean number per person (SD) | 115.1 (300.9) | 134.9 (318.3)$^{**}$ | | 104.9 (262.9) | |
| Interprofessional Consultation activity, external | N (%) | 124,194 (42.1) | 4,142 (59.1) | 2.06(1.97–2.16)$^{**}$ | 2,276 (53.3) | 1.68 (1.58–1.78)$^{**}$ |
| | Mean number per person (SD) | 6.2 (12.0) | 9.5 (16.3)$^{**}$ | | 7.5 (13.7)$^{**}$ | |

**Table 4.3.** continued

| | | No ID<br>N=329,864 | MID<br>N=7,596 | OR (CI 95%)[a] | MID No ID registration N=4,605 | OR (CI 95%)[b] |
|---|---|---|---|---|---|---|
| Legal activity, N (%) | | 11,272 (3.8) | 494 (6.9) | 2.00 (1.82–2.19)$^{**}$ | 222 (5.2) | 1.55 (1.27–1.67)$^{**}$ |
| No-show activity, N (%) | | 27,183 (9.2) | 739 (10.3) | 1.17 (1.08–1.26)$^{**}$ | 406 (9.5) | 1.05 (0.95–1.16) |
| **Crisis intervention** | | | | | | |
| Crisis intervention | N (%) | 68,489 (20.8) | 2,501 (32.9) | 2.00 (1.90–2.10)$^{**}$ | 1,479 (32.1) | 1.93 (1.81–2.05)$^{**}$ |
| | Mean number per person (SD) | 6.7 (9.0) | 6.4 (10.6) | | 5.6 (7.7)$^{**}$ | |
| **MH hospital admission** | | | | | | |
| MH hospital admission | N (%) | 45,001 (13.6) | 1,551 (20.4) | 1.72 (1.63–1.82)$^{**}$ | 698 (15.2) | 1.20 (1.10–1.30)$^{**}$ |
| | Mean admission time per admission in days (SD) | 36.3 (55.0) | 39.2 (61.8) | | 54.7 (76.9) | |

MID: mild intellectual disability; ID: intellectual disability; OR: odds ratio; MH: mental health; MH trajectory: the period in which patients receives MH care for a specific diagnosis in an MH service; Direct patient care: activities with direct patient involvement; Indirect patient care: activities without direct patient involvement; Interprofessional consultation activity, internal: consultations between professionals inside the MH service setting; Interprofessional consultation activity, external: consultations between professionals outside the MH service setting; $^{**}$P<.001; $^{*}$P<.05; [a] MID vs no ID; [b] MID without ID registration compared with no ID.

## Discussion

This is the first population-based database study to focus on patients with MID in advanced MH services. Patients with MID, compared to patients without ID, were diagnosed with different MH disorders and more often received treatment in specialised MH service settings, such as forensic or addiction care. The MH trajectories were shorter, and the MH service professionals performed fewer diagnostic and treatment activities in patients with MID, in particular in those cases in which the ID was unregistered, while conducting significantly more indirect patient care activities. At the same time, crisis interventions and MH hospital admissions were more frequent in patients with MID. These findings are indications of undertreatment in patients with MID, which is likely to result in poor MH outcomes. A total of 60% of the patients with MID had no ID registration in their MH service files. Through linkage with information on MID registration from other sources, we were able to include them in this study.

### Comparison with existing literature

The observed differences in the prevalence of MH disorders in patients with MID compared to patients with no ID, including 'Schizophrenia and other psychotic disorders' (10.9 vs 5.2%), 'Depressive disorders' (10.7 vs 22.6%), and 'Personality disorders' (7.1 vs 13.7%), are consistent with other research in MH services. [7, 15-17] There are several possible explanations for these prevalence differences, including an etiological origin. However, misinterpretation or mis-categorisation of symptoms by referring health professionals, such as the general practitioner and MH service professionals, most likely contribute to differences in prevalence; impaired communication and symptom presentation can make it more difficult to categorise using the DSM. [18] The high prevalence of 'No or unknown diagnosis' in patients with MID (37.4%) is an extra indication in this respect.

Adequate recognition of MID also appeared difficult in MH care. The under-registration of MID in our data, which was also found in other research, [7, 15] can be seen as a clear indication of under-recognition of MID in MH services. The presence of an MID should be taken into account during the whole MH trajectory, as it is considered a significant risk factor for developing chronic and more severe MH problems.[15, 16] The under-recognition of MID in combination with the observed indications of undertreatment in patients with MID in our study is therefore worrying. Undertreatment within MH services can lead to more chronic MH problems and may partly explain a high prevalence of MID in the long-stay wards,[16] but also contributes to high care use in general, illustrated by high primary care consumption[19] and emergency department visits[20] by patients with combined MID and MH problems.

Indeed, observed signs of undertreatment are more prominent in patients whose ID was unregistered. This undertreatment is reflected in shorter MH trajectories (252.9 vs 325.7 days) and fewer diagnostic (73.7 vs 79.7%) and treatment (59.9 vs 78.0%) activities compared to patients with no ID. A systematic review of studies in addiction care settings also indicated undertreatment in people with MID.[21] Compared to patients without ID, they were less likely to initiate and engage in treatment for substance abuse, were more likely to drop out, and treatment was often not adapted to their intellectual capacities. Research in patients with borderline ID (IQ 70–84) and MH problems showed that these patients also were less likely to receive treatment compared to adults with no ID.[22] In this light, the higher prevalence of MH hospital admissions (20.4%) and crisis interventions (32.9%) in our study, confirmed in earlier research,[15, 22] are extra disconcerting findings. Although these could also be reflections of more severe and complex MH problems experienced by patients with MID, following this reasoning we should also have observed longer MH trajectories and a higher occurrence of treatment activities in patients with MID. However, both these aspects are contradictory to our findings.

Our results show that collaboration, reflected in the high number of interprofessional consultations, is often required in MH services, especially regarding patients with MID. Despite the fact that collaboration is seen as a tool to improve (mental) health care and may reduce hospital admissions and costs,[4, 15, 23-25] interprofessional collaboration and other forms of indirect patient care in MH services have never before been the subject of a database study.

## Implications for research and/or practice

There is growing awareness within MH services of the high prevalence of MH disorders in people with MID and the different care needs of this group. Country-specific guidelines have been developed for these patients,[26, 27] and some examples of good practices are noticed [4, 28-30] as well as increasing attention on adapted treatment modules in research.[21, 31] Nevertheless, judging from the results of our study, further steps to improve the MH care for people with MID are needed, not only at care professional level, but also at scientific, organisational, and policy level.

MH service professionals should be aware of the importance of identifying and registering MID, primarily for good care provision, but also for research purposes. Recurrent education programmes on this topic for MH service professionals can be an important tool to improve this awareness. Also, screening for ID in the intake procedure can help to identify an MID at an early stage, enabling adjustments in communication and in diagnostic and treatment protocols from the start. Some useful ID screening tools developed for this purpose are applicable in MH services, but they need to be further implemented in daily practice.[16, 32] At scientific level, adequate ID registration enables researchers to learn in more detail about patient-, care professional-, and organisation-related factors that contribute to observed differences in health and care provided to patients with MID and without ID. Given the diagnostic classification difficulties indicated by our study, further research is needed on the applicability of classification instruments for MH symptoms in patients with MID. In so doing, it is important to focus not solely on the DSM, but also on alternatives, such as Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities (DC-LD),[33] Diagnostic Manual Intellectual Disability (MD-ID-2),[34] or Dôsen's integrative approach.[35] Finally, also at organisational and policy level, steps need to be taken to improve the quality of MH services for patients with MID. In daily practice, this can already be achieved by using existing instruments like The Green Light Toolkit, an audit instrument for MH services developed in the UK,[36] to improve the accessibility of MH services, but investment in initiatives on optimal, country-specific, collaborative MH healthcare models, including incentives for payment, will also contribute in this matter.

## Strengths and limitations

An important strength of this study is the unique focus on people with MID. By linking the SN-MH service database with the SN-MID database, we were able to identify and include people with MID who were not recorded as such in MH services. This fills a blind spot regarding the large number of people with MID who would have been overlooked without data linkage.

The use of databases containing routinely collected (health) data, however, also comes with some limitations. Firstly, the MH service database has limited details of diagnoses and treatments, as the main purpose of the data is to enable proper functioning of the health insurance system. Therefore, only information about the prevalence of main diagnostic groups could be determined, not allowing precise comparisons with international evidence. Secondly, we excluded patients whose MH trajectory end date was missing or whose trajectory was not completed within the period observed in this study. Potentially, this concerned patients with more chronic MH disorders and additional care needs, which might be more prevalent among patients with MID. However, the MID prevalence was lower in the excluded patient group compared to the included patient group (1.9 vs 2.3%; Figure 1). Therefore, we do not think that this has led to a disproportionate exclusion of MID patients and consequently an underestimation of the care provided to those patients in comparison to patients without ID. Thirdly, the SN-MID database is composed mostly of users of work-related social services, resulting in an underrepresentation of children and older people. Therefore, we had to restrict our study population to 18-to-75-year-olds. Finally, the SN-MID database contains no exact information on individual-level intellectual and adaptive functioning, so it cannot be ruled out that some people with more severe ID or borderline intelligence were part of our MID group. However, the SN-MID database is currently the best source available in the Netherlands to identify people with MID. This makes this study unique and valuable, as it is the first population-based database study to focus on the care for people with MID in MH services.

## Conclusion

In conclusion, we can say that MID is very often not registered in MH services and most likely insufficiently taken into account in the trajectories in MH services. People with MID were diagnosed with different MH problems and, particularly in those cases in which the ID was unregistered, provided with fewer diagnostic and treatment activities in MH services, compared to people without ID. This is an indication of undertreatment, likely contributing to the high number of crisis interventions and MH hospital admissions. This underlines the relevance of improving the quality of MH care for people with MID, which can be achieved by creating more professional awareness and (evidenced-based) knowledge of the importance of timely MID recognition and adjustments needed in diagnostics and treatment protocols. In addition, actions are needed at organisational and policy level to create accessible and effective MH services for patients with MID.

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# Supplementary

**Supplementary table 4.1.** Diagnostic groups

| DIS code[a] DSM-IV | Description DIS code[a] | Diagnostic groups pre-defined by Statistics Netherlands |
|---|---|---|
| *as1_1* | *disorders with onset usually occurring in childhood and adolescence* | |
| as1_1.01 | Specific developmental disorders of scholastic skills | Other disorders of childhood |
| as1_1.02 | Specific developmental disorder of motor function | Other disorders of childhood |
| as1_1.03 | Specific developmental disorders of speech and language | Other disorders of childhood |
| as1_1.04 | Pervasive developmental disorders | Pervasive development disorders |
| as1_1.05 | Attention-deficit hyperactivity disorders | Attention deficit and conduct disorders |
| as1_1.06 | feeding disorders of infancy and childhood | Other disorders of childhood |
| as1_1.07 | Tic disorder | Other disorders of childhood |
| as1_1.08 | Enuresis/ Encopresis | Other disorders of childhood |
| as1_1.09 | Other behavioral and emotional disorders with onset usually occurring in childhood and adolescence | Other disorders of childhood |
| *as1_2* | *Delirium, dementia, amnesia and other cognitive disorders* | |
| as1_2.01 | Delirium | Neurocognitive disorders |
| as1_2.02 | Dementia | Neurocognitive disorders |
| as1_2.03 | Amnestic disorder | Neurocognitive disorders |
| as1_2.04 | Other cognitive disorders | Neurocognitive disorders |
| *as1_3* | *Other mental disorders due to known physiological condition* | |
| as1_3.01 | Catatonic disorder due to known physiological condition | Other diagnoses |
| as1_3.02 | Personality and behavioral disorders due to known physiological condition | Other diagnoses |
| as1_3.03 | Unspecified mental disorder due to known physiological condition | Other diagnoses |
| *as1_4* | *Mental and behavioral disorders due to psychoactive substance use* | |
| as1_4.01 | Alcohol related disorders | Alcohol related disorders |
| as1_4.02 | Amphetamine related disorders | Other substance related disorders |
| as1_4.03 | Caffeine related disorders | Other substance related disorders |
| as1_4.04 | Cannabis related disorders | Other substance related disorders |

**Supplementary table 4.1.** continued

| DIS code[a] DSM-IV | Description DIS code[a] | Diagnostic groups pre-defined by Statistics Netherlands |
|---|---|---|
| as1_4.05 | Cocaine related disorders | Other substance related disorders |
| as1_4.06 | Hallucinogen related disorders | Other substance related disorders |
| as1_4.07 | Inhalant related disorders | Other substance related disorders |
| as1_4.08 | Nicotine related disorders | Other substance related disorders |
| as1_4.09 | Opioid related disorders | Other substance related disorders |
| as1_4.10 | Fencyclidine related disorders | Other substance related disorders |
| as1_4.11 | Sedative, hypnotic, or anxiolytic related disorders | Other substance related disorders |
| as1_4.12 | Multiple psychoactive substance related disorders | Other substance related disorders |
| as1_4.13 | Other psychoactive substance related disorders | Other substance related disorders |
| *as1_5* | *Schizophrenia and other psychotic disorders* | |
| as1_5.01 | Schizophrenia | Schizophrenia and other psychotic disorders |
| as1_5.02 | Schizophreniform disorder | Schizophrenia and other psychotic disorders |
| as1_5.03 | Schizoaffective disorders | Schizophrenia and other psychotic disorders |
| as1_5.04 | Delusional disorders | Schizophrenia and other psychotic disorders |
| as1_5.05 | Brief psychotic disorder | Schizophrenia and other psychotic disorders |
| as1_5.06 | Shared psychotic disorde | Schizophrenia and other psychotic disorders |
| as1_5.07 | Psychotic disorder due to known physiological condition | Schizophrenia and other psychotic disorders |
| *as1_6* | *Mood disorders* | |
| as1_6.01 | Depressive disorders | Depressive disorders |
| as1_6.02 | Bipolar and related mood disorders | Bipolar and related mood disorders |
| *as1_7* | *Anxiety and stress related disorders* | |
| as1_7.01 | Panic disorder without agoraphobia | Anxiety disorders |
| as1_7.02 | Panic disorder with agoraphobia | Anxiety disorders |
| as1_7.03 | Agoraphobia without panic disorder | Anxiety disorders |
| as1_7.04 | Specific (isolated) phobias | Anxiety disorders |
| as1_7.05 | Social phobias | Anxiety disorders |
| as1_7.06 | Obsessive-compulsive disorder | Anxiety disorders |

**Supplementary table 4.1.** continued

| DIS code[a] DSM-IV | Description DIS code[a] | Diagnostic groups pre-defined by Statistics Netherlands |
|---|---|---|
| as1_7.07 | Post-traumatic stress disorder | Anxiety disorders |
| as1_7.08 | Acute stress reaction | Anxiety disorders |
| as1_7.09 | Generalized anxiety disorder | Anxiety disorders |
| as1_7.10 | Anxiety disorder due to known physiological condition | Anxiety disorders |
| as1_7.11 | Substance related anxiety disorder | Anxiety disorders |
| as1_7.12 | Anxiety disorder, unspecified | Anxiety disorders |
| *as1_8* | *Somatoform disorders* | |
| as1_8.01 | Somatization disorder | Somatic symptom disorders |
| as1_8.02 | Undifferentiated somatoform disorder | Somatic symptom disorders |
| as1_8.03 | Conversion disorders | Somatic symptom disorders |
| as1_8.04 | Pain disorders related to psychological factors | Somatic symptom disorders |
| *as1_10* | *Dissociative and conversion disorders* | |
| as1_10.01 | Dissociative amnesia | Other diagnosis |
| as1_10.02 | Dissociative fugue | Other diagnosis |
| as1_10.03 | Dissociative identity disorder | Other diagnosis |
| as1_10.04 | Depersonalization-derealization syndrome | Other diagnosis |
| as1_10.05 | Dissociative and conversion disorder, unspecified | Other diagnosis |
| *as1_11* | *Sexual dysfunction* | |
| as1_11.01 | Hypoactive sexual desire disorder | Other diagnosis |
| as1_11.02 | Sexual arousal disorders | Other diagnosis |
| as1_11.03 | Orgasmic disorder | Other diagnosis |
| as1_11.04 | Vaginismus/ Dyspareunia | Other diagnosis |
| as1_11.05 | Sexual dysfunction due to physiological condition | Other diagnosis |
| as1_11.06 | Sexual dysfunction due to a substance | Other diagnoses |
| as1_11.07 | Paraphilias | Other diagnoses |
| as1_11.08 | Gender identity disorders | Other diagnoses |
| as1_11.09 | Unspecified sexual dysfunction | Other diagnoses |
| *as1_12* | *Eating disorders* | |
| as1_12.01 | Anorexia nervosa | Feeding and eating disorders |
| as1_12.02 | Bulimia nervosa | Feeding and eating disorders |
| as1_12.03 | Eating disorder, unspecified | Feeding and eating disorders |
| *as1_13* | *Sleep disorders* | |

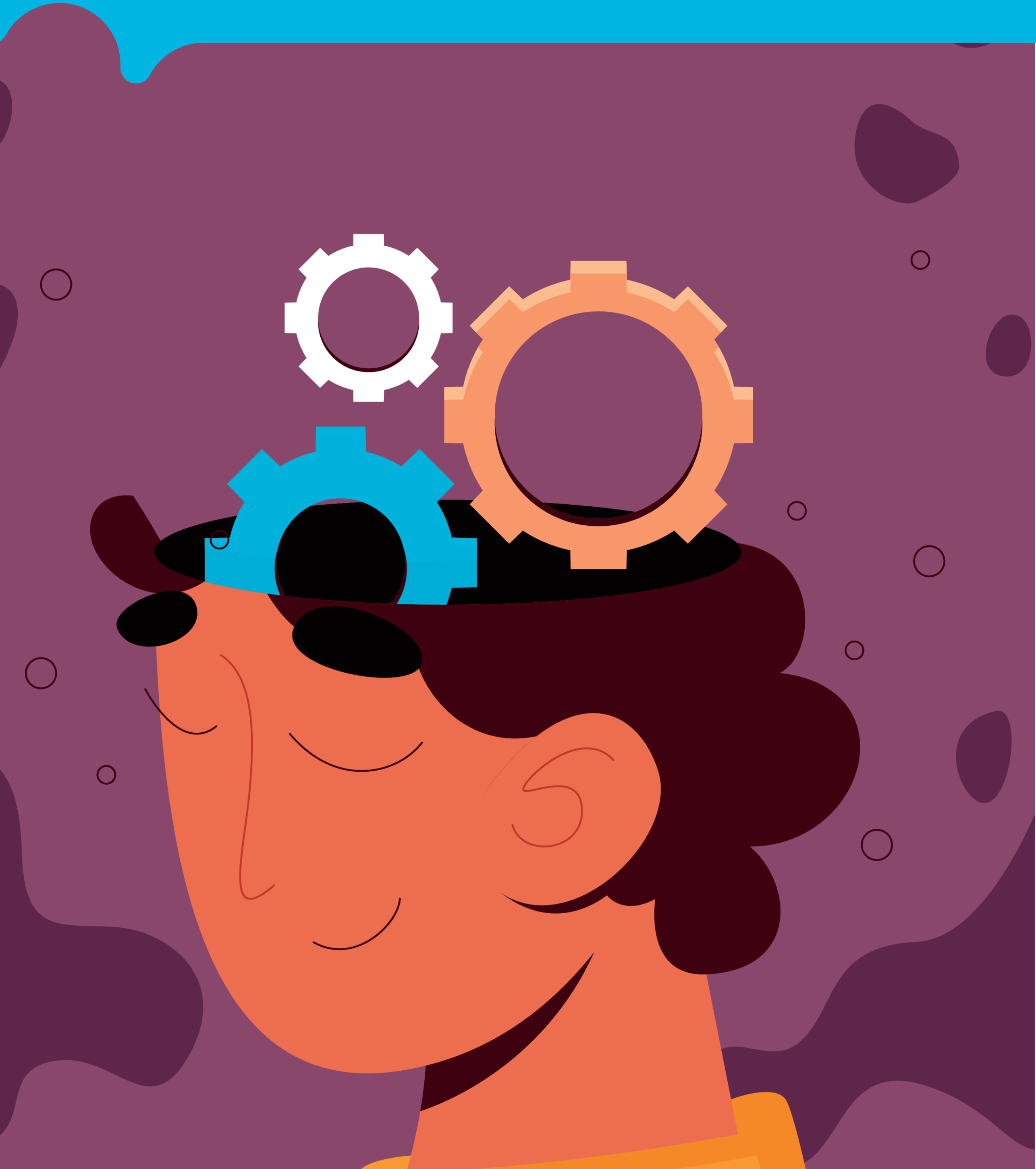
**Supplementary table 4.1.** continued

| DIS code[a] DSM-IV | Description DIS code[a] | Diagnostic groups pre-defined by Statistics Netherlands |
|---|---|---|
| as1_13.01 | Primary sleep disorders | Other diagnoses |
| as1_13.02 | sleep disorders  due to other mental disorder | Other diagnoses |
| as1_13.03 | Other sleep disorders not due to a substance or known physiological condition | Other diagnoses |
| as1_13.04 | Other sleep disorders not due to a substance | Other diagnoses |
| as1_13.07 | Sleep disorder,  unspecified | Other diagnoses |
| *as1_14* | *Impulse disorders* | |
| as1_14.01 | Intermittent explosive disorder | Other diagnoses |
| as1_14.02 | Kleptomania | Other diagnoses |
| as1_14.03 | Pyromania | Other diagnoses |
| as1_14.04 | Pathological gambling | Other diagnoses |
| as1_14.05 | Trichotillomania | Other diagnoses |
| as1_14.06 | Impulse disorder, unspecified | Other diagnoses |
| as1_14.07 | Other impulse disorders | Other diagnoses |
| *as1_15* | *Adjustment disorders* | |
| as1_15.01 | Adjustment disorders | Conducting disorders[b] |
| *as1_17* | *Other problems that are a reason for concern* | |
| as1_17.01 | Psychological and behavioral factors associated with disorders or diseases classified elsewhere | Other problems that are a reason for concern |
| as1_17.02 | Drug-induced extrapyramidal and movement disorders | Other problems that are a reason for concern |
| as1_17.03 | Unspecified adverse effect of drug or medicament | Other problems that are a reason for concern |
| as1_17.04 | problems related to primary support group | Other problems that are a reason for concern |
| as1_17.05 | Problems related to abuse or neglect | Other problems that are a reason for concern |
| as1_17.06 | Additional problems that are a reason for concern | Other problems that are a reason for concern |
| *as1_18* | *Additional code/no diagnosis* | |
| as1_18.01 | Unspecified mental disorder | Other diagnoses |
| as1_18.02 | No diagnose | Other diagnoses |
| as1_18.03 | Diagnose postponed | Other diagnoses |
| *as1_19* | *Primary childhood disorder* | |
| as1_19.01 | Post-traumatic stress disorder, childhood | Other diagnoses |
| as1_19.02 | Affective disorders, childhood | Other diagnoses |
| as1_19.03 | Adjustment disorders, childhood | Other diagnoses |
| as1_19.04 | Regulation disorders, childhood | Other diagnoses |

**Supplementary table 4.1.** continued

| DIS code[a] DSM-IV | Description DIS code[a] | Diagnostic groups pre-defined by Statistics Netherlands |
|---|---|---|
| as1_19.05 | Sleep disorders, childhood | Other diagnoses |
| as1_19.06 | Eat disorders, childhood | Other diagnoses |
| as1_19.07 | Relation and communication disorder, childhood | Other diagnoses |
| *as2_16* | *Personality disorders* | |
| as2_16.01 | Cluster A personality disorders | Personality disorders |
| as2_16.02 | Cluster B personality disorders | Personality disorders |
| as2_16.03 | Cluster C personality disorders | Personality disorders |
| as2_16.04 | Personality disorders, unspecified | Personality disorders |

[a] DIC code: represents diagnosis treatment combination products that can be claimed by the Dutch insurance compagnies. The codes are determined by the Dutch Healthcare authority and are linked to diagnoses established in *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (DSM-IV); [b] Due to changes in financing this diagnostic group conducting disorder' is no longer used and therefore not taken into account in this study



# Chapter 5

# Primary mental healthcare for adults with mild intellectual disabilities: patients' perspectives

Pouls KPM, Mastebroek M, Ligthart SJ, Assendelft WJJ, Leusink GL,
Koks-Leensen MCJ.
Primary mental healthcare for adults with mild intellectual disabilities:
patients' perspectives.
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# Abstract

**Background:** People with mild intellectual disabilities (MID) experience more mental health (MH) problems than the general population, but often do not receive appropriate primary MH care. Primary MH care is essential in integrative MH care and therefore demands high quality. To improve primary MH care for this patient group, account must be taken of the experiences of people with MID themselves. So far, their perspectives have been largely absent from primary MH care research.

**Objective:** To explore patients' experiences, needs, and suggestions for improvement regarding primary MH care for people with MID.

**Method:** A qualitative study among adults with MID who visited their GP with MH problems in the previous 12 months. Semi-structured interviews were conducted using a guide based on Person-Centred Primary Care Measures. Transcripts were analysed thematically.

**Results:** The 11 interviews that we conducted revealed four themes. The first theme, cumulative vulnerability, describes the vulnerability – instigated by the MID and reinforced by MH problems – experienced on a GP visit. The other themes (needs regarding the GP, needs regarding the network, self-determination) arise from this vulnerability.

**Conclusion:** People with both MID and MH problems are extra vulnerable in primary care but desire self-determination with regard to their MH care trajectory. This requires investment in a good GP–patient relationship and the organisation of additional support to meet these patients' needs, for which collaborative care with the patient, the patient's network, and other (care) professionals is of utmost importance.

# Introduction

People with mild intellectual disabilities (MID) are at high risk for mental health (MH) problems,[1] but often do not receive appropriate MH care.[2-5] As a result, people with MID may develop MH problems of a more severe or chronic nature, putting a high burden on people's lives.[6]

MID is characterised by significant limitations in both intellectual functioning and adaptive skills, with onset during childhood.[7, 8] Despite no intelligence quotient (IQ) range being included in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) definition of MID,[8] the 50–70 IQ range is often adhered to internationally, representing a significant limitation in intellectual functioning. However, in some countries, including the Netherlands, a broader definition of MID is used. This broader definition includes an IQ range from 50 to 85, with such limitations in adaptive skills that support is needed to function adequately in daily life.[9] For this article, we used this broad MID definition.

In countries with a primary care model, such as the UK and the Netherlands, general practitioners (GPs) are the first point of encounter for people with MH problems and have an important role in detection, treatment, and follow-up. Primary MH care is seen as a key element of integrative MH care, which involves task-sharing with MH services and other care providers.[10] In the Netherlands, it is estimated that approximately 6.4% of the Dutch population have MID according to the broad MID definition,[11] of whom up to a third experience MH problems.[1] Most people in this MID group live in the community and receive primary (MH) care from local GPs, mostly supported by a mental health nurse practitioner (MHNP). Previous research shows that GP practices often do not recognise the presence of MID in patients.[12] Although GPs acknowledge their role in MH care in general, they do not always feel equipped to provide this care,[13, 14] feeling even less competent providing care to people with a combination of MID and MH problems.[5, 15, 16]

In the Netherland, people with both MID and MH problems have a high use of primary care services; they receive more consultations and are prescribed more psychotropics than people without ID or with MID alone. This puts a high demand on primary care practices.[12]

A recent review confirms GPs' vital role in providing care to people with MID and MH problems but also indicates that current GP care is often insufficient in terms of underdiagnosis of MH disorders, overmedication, and lack of effective patient follow-up.[5] None of the included publications focused on patients' perspectives concerning primary MH care for people with MID.[5] Some studies focused on patients' perspectives on general primary care for people with (M)ID and on primary MH care in general. In these studies, patients with MID indicate that the use of simple language, sufficient time, and the GP's familiarity with patients with MID facilitate accessibility and consultations in primary care.[17, 18] Patients with MH problems, but without MID, emphasise the importance of feeling heard, known, and safe at their GP.[19] In light of the above, we expect that the combination of MID and MH problems will entail greater or additional needs regarding the GP.

To our knowledge, there are as yet no studies exploring the perspectives of patients with MID regarding primary MH care. In order to improve primary MH care in line with the needs of such patients, it is important to stay close to the real-life experiences of patients to whom this care is provided. Therefore, the aim of this study is to explore patients with MID's experiences, needs, and suggestions for improvement regarding primary MH care.

## Method

### Setting and sample

For this interview study, we recruited adult patients with MID and MH problems enrolled in GP practices in various Dutch regions between May and October 2022. Our recruitment strategy entailed convenience sampling by sending informational study brochures and flyers to our professional networks within the following organisations: the Radboudumc Academic GP network, national GP and MHNP organisations, and advocacy organisations for people with MID. Candidates could apply directly or through their GP or MHNP. Selection criteria for inclusion were: having visited a general practice with MH problems in the previous 12 months, being communicative and mentally capable of participating in an interview, and having a confirmed MID or strongly suspected of having one by their GP or MHNP.

Candidates received easy-to-read study information, and both written and verbal informed consent were obtained prior to the interview. If they had a legal representative, the representative's consent was additionally required before participation.[20] In order to create an environment in which the participants felt as free as possible to talk about their own experiences and needs regarding this sensitive subject, interviews were conducted at a location of the participant's choice, including the option of an online interview, and accompanied by a trusted person when desired. When a trusted person was present, that person did not participate actively in the interview, and his or her personal opinion was not considered in the data analysis. Participants were offered a €15 gift voucher after the interview. The Medical Research Ethics Committee East-Netherland, registration number: 2022-13687, ruled that this study was not subject to the Medical Research Involving Human Subjects Act.

### Data collection

Semi-structured interviews followed an interview guide based on the 11 dimensions of the Person-Centred Primary Care Measures (PCPCM, Supplementary Table 1).[21] The PCPCM is a patient-reported instrument encompassing 11 primary care aspects considered responsible for primary care effects on population health, equity, quality, and sustainable expenditure. A twelfth dimension, self-determination, was added to the interview guide after expert consultation of the study's advisory group, which consisted of representatives from patient associations, primary care, ID care, MH care, and addiction care. Self-determination, the freedom to make one's own choices, whether or not supported by carers, is associated with higher psychological wellbeing in people with MID[22] and is described in the Convention on the Rights of Persons with Disabilities.[23]

The interviews were guided around the patient journey in primary care, starting with accessing primary care, followed by assessment, diagnosis, and treatment plan including referrals and medication prescriptions, and follow-up. A co-researcher (AC) with MID was involved in drafting the interview guide to ensure the clarity of the questions and the adequacy of the sequence of topics for the participants. In order to tailor the interview to each specific participant, prior to the interview, basic information on the MH care provided was retrieved through the patients and, when there was patient consent, their GP. This information consisted of type of MH problem and whether or not the MHNP was involved, the patient was referred, and medication was prescribed. All interviews were conducted by the same female researcher (KP) who is an ID physician with broad experience in communicating with people with MID.

### Analysis

The interviews were audio-recorded and transcribed verbatim. The transcripts were analysed following the principles of thematic analysis, [24] supported by ATLAS.ti software (version 22.0.11). Coding was conducted by two researchers independently (KP and MK or MM). Codes were then collated in preliminary themes and repeatedly discussed in the research team (KP, MK, MM, SL, WA, GL) to refine and define the themes. Before the final themes were established, they were discussed and deliberated with the study's advisory board. The COREQ criteria list for qualitative research was used to guide the analysis and report. [25]

## Results

In total, 11 persons with MID, of whom ten females, were interviewed between June 2022 and October 2022, age range 23–63 years. The duration of the interviews was 40 to 70 minutes, one interview took place online, and in three interviews there was a trusted person present. Eight participants received care from an MHNP in the primary care setting (Table 5.1).

The analysis resulted in four not-mutually exclusive themes. The first, overarching, theme is cumulative vulnerability, relating to the vulnerability – instigated by their MID and reinforced by MH problems – experienced by the participants visiting their GP. Three themes further describe the needs that arise from this vulnerability: patient needs regarding the GP, patient needs regarding the network, and self-determination regarding the MH trajectory (Box 1). Our analysis showed that within these themes, self-determination excluded, three levels – cognitive, practical, and emotional – could be identified. For the sake of readability, GP is stated where it applies to both GP and MHNP. When necessary, GP or MHNP is specified.

**Table 5.1.** Characteristics of participants

| Participant | Sex[1] | Age | MH problem[2] | MHNP[3] involved | Psychotropic(s) prescribed | Referred to MH[2] services | Trusted person present | Online / face-to-face[4] |
|---|---|---|---|---|---|---|---|---|
| **1** | F | 62 | Mood problems | X | | X | | FF |
| **2** | F | 63 | Anxiety | X | X | X | X | FF |
| **3** | F | 28 | Borderline personality<br>Autism<br>Mood problems | | X | X | | O |
| **4** | F | 49 | Trauma<br>Mood problems | X | | X | | FF |
| **5** | F | 26 | Anxiety | X | | X | | FF |
| **6** | F | 38 | Trauma | X | X | X | | FF |
| **7** | F | 50 | Depression<br>Panic<br>Trauma | X | X | X | | FF |
| **8** | F | 53 | Trauma | X | X | X | X | FF |
| **9** | F | 61 | Mood problems<br>Trauma | X | X | X | | FF |
| **10** | M | 51 | Sleep problems | | X | X | X | FF |
| **11** | F | 23 | Stress | | | | | FF |

[1]Sex: M: male, F: female; [2]MH: mental health problem accordingly to the GP or the participant; [3]MHNP: mental health nurse practitioner; [4]Online/face-to-face: O: interview was held online, FF: interview was held face-to-face

### *Theme 1: Cumulative vulnerability*

Participants experienced a wide range and accumulation of additional barriers and problems occurring in their lives when experiencing MH problems, creating cumulative vulnerability. Compared with GP consultations for somatic problems, most participants experienced extra difficulties visiting their GP for MH problems. These entailed, on a cognitive level, finding it hard to recognise MH problems in the first place and, secondly, to assess whether or not to visit a GP for these problems.

> *If you have an ear ache or a stomach ache, you just think that these things often happen. But now I wondered if there really was something wrong with me. Am I not exaggerating? (P1)*

Further, participants encountered communication problems during GP consultations, because the GP took insufficient account of the MID. The GP used difficult language, had limited time, did not repeat the given information frequently enough, and provided general information on MH problems that the participants found difficult to apply to their own specific situation. For example, one participant experienced MH problems after she lost contact with her mother. In this context, the MHNP used a term unclear to her:

> *Then she said that this was a 'grieving process'. That wasn't completely clear to me. (P5)*

On both a cognitive and a practical level, participants appeared vulnerable with regard to healthcare access and utility of care. For a number of participants, it was not clear that a GP was accessible for MH problems, other than for a specific question about medication.

> *It feels strange. You think that if you have a stomach ache, you can look for help. But if you have other, mental problems then you wonder where you can go. You just don't know. (P4)*

After the consultation, it was frequently not possible for participants to follow GP advice. Advice did not sufficiently meet participants' expectations or was too difficult to implement in their daily lives and was therefore not followed at all. One participant, for example, had been advised to write down her thoughts, which she was not able to do:

> *But at that moment I also had to write things. But that didn't really work for me. (P5)*

Finally, participants often lacked a network offering the practical and emotional support needed to implement GP advice following GP contacts. Often, no network was available, or participants experienced poor relations with their network. Also, MH problems themselves could be perceived as a barrier to involving network relations: participants indicated feeling uncomfortable talking about their MH in the presence of the network; and others, as can be seen in the next quote, did not want to burden their spouse with their problems.

> *I can't bother my husband with this. He has enough problems with me now as it is. Because of this [the MH problems], my relationship isn't as good as it should be. (P9)*

MH problems are often accompanied by strong emotions that, according to the participants, make it even more difficult to open up to their GP and express their symptoms.

> *Usually, if I'm sad then I just shut down. And then they [the GP and the MHNP] know that they sometimes have to drag the words out of me. And that I lie a little bit then sometimes. Then I just avoid things and say that there isn't a problem. (P11)*

In addition, participants had concerns about being stigmatised by MH problems or misunderstood by their GP, and that, once they were known to have MH problems, somatic problems would be dismissed as psychological.

> *That they'll just take pity on you and then you get a 'P' on your medical record … so that all of your problems are seen as psychiatric. (P1) [Category P in primary care coding stands for 'known to have MH problems', note author KP]*

These concerns could be reinforced by negative past experiences with GPs, but also with MH services and their support network. Finally, participants found it difficult to express dissatisfaction with a consultation or advice, or to acknowledge that they did not understand the information given, mainly because of a feeling of shame and fear of disrupting the doctor–patient relationship.

### *Theme 2: Patient needs regarding the GP*

Participants considered it important for the GP and staff to take the MID into account during communication, without the participant having to remind them of their MID. They would like information provided in easy language, repeated several times, and focused on each patient's specific care situation.

> *...and if there are any information brochures, they're so general. So not specifically for my problems. (P3)*

Participants emphasised the relevance of knowing that the GP is accessible for MH problems as well as for somatic complaints. Easy-to-read information in a leaflet or on the GP website was mentioned as helpful in this respect. In addition, they expect GPs to reply to their needs promptly and to actively support the implementation of given advice, both medical and non-medical.

> *...just like a daycare programme or something like that. You often had to look for one yourself. And sometimes it's great that, for example, the GP knows about a programme somewhere. So you don't have to look for it all by yourself. (P3)*

The GP is expected to oversee and coordinate all care, medical and non-medical, relating to the patient. In the case of referral to MH services, the GP remains the point of contact for the patient's MH problem and is expected to regularly and actively inform both MH services and the patient, and to resolve any barriers to MH care experienced by the patient.

> *And it's very important that the GP questions the organisations. Questions that I myself can't ask. That she does that for me. Or someone else does it for me because I can't do it. Especially if I'm having serious mental problems. (P4)*

All participants mentioned the importance of a good relationship with the GP, which was considered even more valuable when experiencing MH problems than when experiencing somatic problems. A good relationship, which, according to the participants, includes knowledge about the patient's past and context, is seen as a prerequisite for opening up during consultations and accepting and following GP advice.

> *She's like my confidential advisor … I feel safe with my GP … the attention that someone, the feeling that someone actually sees you. For the first time in my life, I talked to someone [about traumas in her youth]. (P4)*

Some participants had a better relation with their MHNP than with their GP. Aspects considered important in this respect concerned the MHNP having more time to talk, the contact being perceived as less formal, and participants being less worried that somatic problems would be dismissed as psychological.

> *When I go to my GP, the appointment is very short … but, when I go to S [MHNP], I can really explain what the problem is. I can talk about things. I need time to talk about the things I want to say, but that isn't possible at the GP's. (P8)*

As participants found it difficult to talk about their MH problems, GPs were expected to initiate questions on MH problems, continue to explore the full details of MH problems, and show initiative to involve the participant's network.

> *Then it's really important to have someone who keeps asking me questions. Also because I'm afraid to say or I don't know if this is something psychological. And that's really difficult for the GP because he or she can't read my mind. (P4)*

### *Theme 3: Patient needs regarding the network*

Participants indicated valuing the opinion and support of their network – both family members and professional carers. Participants need the network for signalising and assessing MH problems, and encouraging contact with the GP when deemed necessary.

> *And then I kept things to myself for a very long time, things like anger. And then my carer said that perhaps I should go back to the MHNP. (P5)*

In addition, participants found it helpful when someone from the network was present during consultations, as the information provided can be repeated by, and discussed with, that person in the home setting.

> *She remembers things better. She's a bit like a second head. So then we talk about it again later. (P5)*

On a practical level, persons from the network can help to tailor GP advice to the patient's daily life.

> *Then she [the GP] gave my carer some tips. And then she wrote some suggestions on a piece of paper, like: what do I do when I feel like this or that? Something like that, those sorts of questions … and my carer developed these further. (P6)*

Participants, however, also desired emotional support from their network, both during and after a consultation, especially when feeling vulnerable to being misunderstood by their GP.

> *Then I felt like no one understood me and I was fed up. And then I contacted a carer … and then I had her explain things for me. (P6)*

### *Theme 4: Self-determination*

Participants emphasised the need for self-determination with regard to their MH trajectory. Despite their vulnerabilities and needs regarding their GP and network, they indicated the wish to establish their own MH treatment plan and actions in close cooperation with the GP.

> *She talks about her ideas and I talk about my ideas and together we find a compromise. (P7)*

If the GP deems it necessary, the network is allowed to be actively involved, as long as the patient can still make his/her own decisions, potentially with support from the network if the patient desires that. Participants argued that this may only be overruled if their mental state demands that.

> *I was really in a bad state so I had to. They had to take action. The GP said 'Now we're going to do this'. … My parents were involved in everything. ... Now that I feel better and can myself explain whether or not I'm okay, my parents no longer go with me to the GP's. (P3)*

**Box 5.1.** The perspective of patients with a mild intellectual disability (MID) on primary mental health (MH) care; four themes[1]

**Theme 1: Cumulative vulnerability**

Vulnerability instigated by patients' MID and reinforced by MH problems.
Barriers and problems experienced:

- Patients themselves recognising and assessing MH problems
- GPs' accessibility for MH problems
- Information transfer between GP and patients affected by lower cognitive skills and emotions
- Translation of GP's advices to daily life
- Limited support from a formal and an informal network
- Concerns about being stigmatised or misunderstood by the GP
- Negative past experiences in care and support

Because of this vulnerability, patients have additional needs and expectations regarding the GP, the network, and self-determination regarding their MH trajectory:

**Theme 2: Needs regarding the GP**

- Tailoring communication to the MID
- Securing the GP is easily accessible for MH problems
- Supporting the implementation of given advices, both medical and non-medical
- Overseeing and coordinating all care related to the participant, both medical and non-medical
- Investing in a good patient–GP relationship
- Having knowledge about the patient and his/her context
- Showing initiative to involve the formal and informal network when needed
- Proactively asking questions about possible MH problems

**Theme 3: Needs regarding the network**

- Signalising MH problems
- Encouraging the patient to visit the GP when deemed necessary
- Support with information transfer, organisational tasks, and translation of GP's advices to daily life
- Providing emotional support

**Theme 4: Self-determination**

Despite their vulnerabilities and additional needs regarding their GP and network, participants expressed the desire for self-determination with regard to their MH trajectory

[1] Themes are not-mutually exclusive

# Discussion

In this interview study we aimed to explore patients with MID's experiences, needs, and suggestions for improvement regarding primary MH care. The results reveal that people with MID feel more vulnerable visiting their GP with MH problems than with somatic problems; this cumulative vulnerability is instigated by their MID and reinforced by MH problems. This translates into various needs and expectations regarding the patient's GP, family, and professional carers, but the need for self-determination remains important.

## Strengths and limitations

To our knowledge, this is the first study to focus on perspectives of patients with MID and MH problems in primary care. To optimise the quality of data collection, interview questions were grounded in the PCPCM structure, evaluated by the study's advisory board, and simplified and adjusted with the help of a co-researcher with MID. In addition, the interviews were conducted by a researcher who, as an ID physician, has great experience in discussing sensitive topics with people with MID. To optimise the quality of data analysis, the research team and advisory board were composed of professionals from diverse backgrounds: patient associations, primary care, ID care, MH care, addiction care, and a research institute. This ensured that various perspectives were included in the data aggregation and theme formation. The discussion among these professionals ensured that personal experiences and related convictions of the research team could only minimally influence the interpretation of the results.

Participants were asked to reflect upon their experiences with primary MH care in the past – an exercise that might lead to recall bias. We minimised this by including only people who had received primary MH care in the previous 12 months. In addition, selection bias may have occurred for a number of reasons. First, precise information on participants' intellectual and adaptive functioning was not available. Theoretically, persons with more severe ID or without ID may have been included as participants. However, the expert judgement of the clinical-researcher, an ID physician, qualified all participants as persons with MID. Secondly, as most participants were recruited through their GP, people whose MID was not identified by the GP were not invited to participate in this study. Thirdly, only people who were communicative and mentally capable could participate. Finally, we were able to include only one male, despite extra efforts to include more male participants. However, there was a good spread in age and type of MH problems among the 11 participants (Table 1) who were contacted across GP practices throughout the country. These biases may have underexposed specific perspectives.

### Comparison with existing literature

Our findings show some similarities with studies focusing on primary care experiences of people with MID alone and of people with MH problems without ID. Like the participants in our study, people with MID in general experience difficulties in contemplating whether or not to visit their GP and in communicating with their GP [17, 26]; issues acknowledged by GPs. [27-29] The support of a network, a good relationship with the GP, continuity of care, and autonomy were also deemed important in previous studies. [17, 27]

In addition, our results overlap with a qualitative study focusing on people in primary care with MH problems in general, where patients also indicated that it is essential to have a good relationship with their GP and for the GP to be familiar with their context and keep up-to-date about their mental wellbeing. [19] In contrast to participants with MID in our study, that study focuses less on practical needs and the role of the network seems less prominent.

### Implications for research and practice

The results of this study provide insight into patients' expectations and needs, and thus offer opportunities to improve the quality of primary MH care for people with MID. Participants expressed the need for the GP and staff to acknowledge their MID. For this, it is important for the GP and staff to recognise a (possible) MID, record this in the patient's file, and adjust their approach and communication accordingly. To accomplish this, it is relevant to invest in associated training programmes for GPs and staff, to create GP awareness of supporting tools such as screeners for (M)ID, for example SCIL and HASI,[30, 31] and to invest in ways to support information exchange.[32]

GPs were expected to initiate questions on MH problems, as participants found it difficult to talk about their MH problems. Although this can be done during any regular GP consultation, we know from previous research that standardised screening for MH problems may be helpful in order to consider MH problems at an early stage.[5] A periodic (mental) health assessment instrument could be a valuable tool in this regard, and some have already been developed and are available for GPs.[16, 33, 34] However, further research on feasibility and (cost-)effectiveness is necessary.

Participants expected the GP to support them with the implementation of medical and non-medical advices in their daily lives. GPs should be aware that people with MID may lack practical skills and ensure the involvement of people providing support. Support may come from the patient's own network, community disability teams, ID care facilities, or, in the Dutch situation, the MHNP or independent client supporters.[35] These supports should be findable and easily accessible for both the GP and the patient, have experience with people with MID, and have a good overview of (care) programmes in the region that are accessible for people with MID.

Some participants found it difficult to coordinate their own care when experiencing MH problems and expected the GP to take on a role as director of their overall longitudinal care, including the organisation of support in daily living situations. However, the question is whether GPs are properly required and equipped to direct this full range of care, especially when the main focus of care is non-medical. Collaborative care with the patient, the patient's network, and other (care) professionals may be more suitable.

Participants expressed the need of a long-term trust relationship with the involved care professionals, and continuity is therefore deemed valuable for this vulnerable patient group. Consequently, the practice organisation should aim at optimal continuity of care provided by the same person. [36] For the GP, this requires extra time and effort, which is not always feasible in daily practice. An MHNP or the patient's own network may be actively involved to support meeting these emotional needs.

Participants desired to maintain self-determination over their MH trajectory in primary care. The ability to make their own decisions contributes to personal wellbeing in people with ID and/or MH problems. [37, 38] To safeguard autonomy in patients with MID, GPs should be aware that this requires additional, patient-tailored, practical and emotional support, taking into account the patient's cognitive skills. Extra consultation time, accessible information, sufficient alternatives, and someone to talk to are seen as essential for decision making [37] and should be facilitated in primary MH care.

Finally, it would be of additional value to study GPs' perspectives on primary MH care for people with MID. This may help ensure that suggested implications for practice are feasible in GPs' daily practice and match these professionals' needs and capacity.

## Conclusion

The patients' perspective shows that people with MID, with additional MH problems, feel extra vulnerable in accessing and utilising primary care, and desire self-determination over their MH. Their perceived vulnerability requires investment in a good GP–patient relationship and the organisation of additional support to meet their needs. This support is especially important for the implementation of GP advices and coordination of care, whereby patients' cognitive, practical, and emotional level of functioning is taken into account. This is not only a task for the GP; it also requires collaborative care with the patient, the patient's network, and other (care) professionals.

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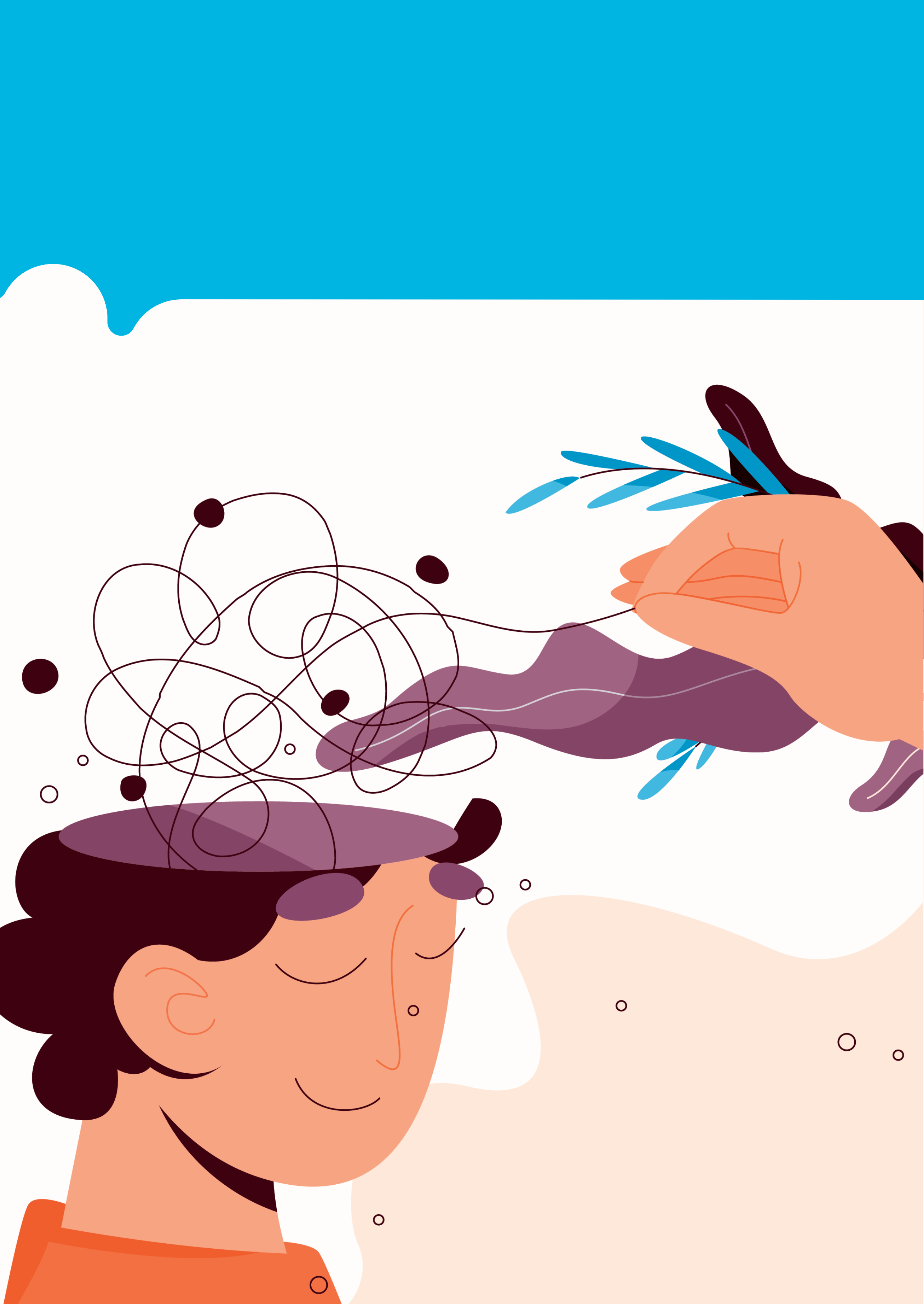
# Supplementary

**Supplementary Table 5.1**. Interview guide

| Standard questions | PCPCM1 dimensions |
|---|---|
| What was it like for you to talk to your GP about your mental problems? | Accessibility<br>Relationship |
| Were you able to talk easily to your GP about your situation? | Comprehensiveness<br>Goal-oriented care<br>Integrating care<br>Family context<br>Community context |
| Could your GP explain the cause of your problems to you? | Relationship<br>Disease, illness, and prevention management |
| How did the GP explain how he or she was going to help you? | Disease, illness, and prevention management<br>Shared decision making<br>Relationship<br>Goal-oriented care<br>Family context<br>Community context<br>Advocacy |
| How did your GP monitor your mental health problems? | Goal-oriented care<br>Continuity of care<br>Advocacy<br>Disease, illness, and prevention management<br>Relationship |
| What or who helps you to remain mentally healthy? | Disease, illness, and prevention management<br>Advocacy<br>Accessibility |
| Have you ever talked with your GP or mental health nurse practitioner about your learning problems/(possible) mild intellectual disability? | Accessibility |
| **Optional questions** | **PCPCM[1] dimensions** |
| What did you think about being given medicine for your problems? | Relationship<br>Disease, illness, and prevention management |
| How did you feel about being referred? | Relationship<br>Comprehensiveness<br>Advocacy<br>Coordination<br>Continuity of care |
| What was it like to be referred to the mental health nurse practitioner? | Relationship<br>Coordination of care<br>Goal-oriented care<br>Comprehensiveness<br>Family context<br>Community context |

[1] Based on 11 Person-Centred Primary Care Measures



# Chapter 6

# Primary mental healthcare for adults with mild intellectual disabilities: care professionals' perspectives

Pouls KPM, Mastebroek M, Ligthart SJ, Assendelft WJJ, Leusink GL,
Koks-Leensen MCJ.
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# Abstract

**Background**: General practitioners (GPs) and mental health nurse practitioners (MHNPs) often feel ill equipped to provide mental health (MH) care to people with mild intellectual disabilities (MID). This is worrying, as insufficient primary MH care may lead to more severe or chronic problems. To improve primary MH care for this patient group, account must be taken of the experiences and needs of GPs and MHNPs providing the care.

**Aim:** To explore GPs' and MHNPs' experiences, needs, and recommendations for improvement regarding primary MH care for adults with MID.

**Design and setting:** Focus group study among GPs and MHNPs.

**Method:** Focus groups, guided by topics based on an interview study with adults with MID receiving primary MH care. Transcripts were analysed by thematic analysis.

**Results:** Four focus groups, with 19 GPs and 9 MHNPs, revealed four themes describing the needs and perceived complexity involved in providing MH care to patients with both MID and MH problems: 1] GPs' and MHNPs' struggles with adapting to challenging patient characteristics; 2] importance and difficulties of establishing a good doctor–patient relationship; 3] facilitating and hampering roles of the patient's network; 4] GPs' and MHNPs' challenges to provide care in the healthcare chain.

**Conclusion:** GPs and MHNPs often experience providing care and support to this patient group as burdensome. It is important to consider the MID throughout the MH trajectory, to invest in a strong doctor–patient relationship, and to establish a stable, sustainable network and coordinated collaborative care around the patient.

## Introduction

In many countries, the general practitioner (GP) is the first point of contact for people with mental health (MH) problems, and the gatekeeper to MH services. However, GPs do not always feel equipped to provide mental health (MH) care to people with mild intellectual disabilities (MID), [1, 2] defined as a significant deficit in intellectual (IQ range 50–85) and adaptive functioning. [3] This is worrying, as insufficient primary MH care in this group may lead to more severe or chronic MH problems. [4]

People with both MID and MH problems put a high demand on primary care practices. [5] The prevalence of MH problems in people with MID is twice that of the general population estimate. [6] Furthermore, this patient group consults their GP more frequently compared with patients without intellectual disabilities (ID) or with MID alone. [5]

Previous research indicates that current primary MH care for people with MID requires improvement. [2] GPs internationally lack evidence-based knowledge and MH screening tools for people with MID, [1, 7] struggle to identify and register the MID, and therefore have difficulty taking the MID into account when establishing the correct MH diagnosis and treatment. [2] This may lead to underdiagnosis, overmedication, and the progression of MH problems. [2, 7]

In order to improve primary MH care, it is important to stay close to the actual experiences of patients to whom this care is provided and of care providers who provide the care. In the Netherlands, this is the GP, often supported by a mental health nurse practitioner (MHNP). An MHNP works under GP supervision, has a role in assessing MH symptoms, and gives short periods of treatment and support to people with mild MH problems.

Results of an interview study revealed that people with both MID and MH problems have various additional needs and expectations regarding their GP, family, and professional carers, but their need for self-determination remains important. This stems from a sense of vulnerability when visiting their GP, which is related to their MID and reinforced by MH problems. [8]

It is known from previous studies that GPs experience difficulties in providing care to patients with solely MID or MH problems,[9-12] leading to the assumption that the combination of MID and MH problems entails even greater or additional difficulties for the GP. We found only one study – exploring the experiences of Norwegian GPs providing care to people with ID – with a special focus on combined ID and MH problems. That study's participants, who had above average experience with people with ID, felt insecure in treating these patients and experienced problems in referring patients when problems became too complex for primary care.[1]

Further knowledge that could guide quality-of-care improvement is lacking, given GPs' and MHNPs' specific needs regarding primary MH care for people with MID. Therefore, the aim of this qualitative study is to explore GPs' and MHNPs' experiences, needs, and recommendations for improvement regarding primary MH care for adults with MID.

# Method

## Setting and sample

To broadly explore GPs' and MHNPs' perspectives on the care provided to patients with MID and MH problems, we conducted a focus group study. We recruited GPs and MHNPs in several Dutch regions in November and December 2022. Our recruitment strategy entailed contacting our personal networks through local GP networks, national GP and MHNP organisations, and LinkedIn. To ensure distribution across the Netherlands, we applied purposive sampling. Varying levels of experience with this patient group were included.

Candidates received study information by e-mail, and written informed consent was obtained. The target number of participants in each focus group was five to ten, and focus groups were conducted at a location of the groups' choice, including online. All participants were offered a €25 gift voucher and postgraduate education accreditation points. The Medical Research Ethics Committee East-Netherlands, registration number: 2022-13687, ruled that this study was not subject to the Medical Research Involving Human Subjects Act.

### Data collection

The focus groups were guided by a topic guide based on four themes emerging from a previous interview study among patients with MID who received primary MH care (Supplement).[8] This topic guide was critically scrutinised by both the research team and the study's advisory group, the latter consisting of representatives from primary care, ID care, MH care, addiction care, and associations for patients with ID. This was done to ensure that GPs' and MHNPs' perspectives were collected as completely as possible.

Prior to the focus group meetings, participants' basic characteristics were ascertained: sex, age, number of years of work experience, and self-perceived level of experience with patients with MID. All focus groups were moderated by the same researcher (KP), who is an ID physician, assisted by a second researcher, either one of two senior researchers (MK, MM) or a PhD candidate (AB).

### Analysis

The focus group discussions were audio-recorded and transcribed verbatim. The transcripts were analysed following the principles of thematic analysis,[13] supported by ATLAS.ti software (version 22.0.11). Coding was conducted by two researchers independently (KP, and MK or MM). Codes were then collated in preliminary themes and repeatedly discussed among the research team (KP, MK, MM, SL, WA, GL) to refine and define the final themes. The COREQ criteria list for qualitative research was used to guide the analysis and the report.[14]

## Results

Nineteen GPs and nine MHNPs participated in four focus groups held in February and March 2023. Their age ranged from 29 to 65 years; 20 were female. The median work experience was eight years (range 1–28 years), and most participants reported low to average experience with people with MID in their practice (Table 6.1). One focus group took place online, the others live.

Overall, the participants perceived their patients with both MID and MH problems as complex patients who, given their high care needs, put pressure on their general practices. Participants felt responsible for this patient group but found it difficult to provide them with the appropriate (MH) care, leading to participants feeling frustration, uncertainty, and despondency. Reasons for the perceived complexity in delivering (MH) care to patients with both MID and MH problems were captured in four main themes emerging from the focus groups: 1] GPs' and MHNPs' struggles with adapting to challenging patient characteristics; 2] importance and difficulties of establishing a good doctor–patient relationship; 3] facilitating and hampering roles of the patient's network; 4] GPs' and MHNPs' challenges to provide care in the healthcare chain (Box 6.1). Below, each theme is described, ending in each case with a box of practice-based insights that, according to the participants, could contribute positively to the quality of care regarding the respective theme (Boxes 6.2–6.5). For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified.

**Table 6.1.** Participants' characteristics

| Nº Focus group[a] | Age (years) | Sex[b] | GP/MHNP[c] | Work experience (years) | Experience with patients with MID[d] |
|---|---|---|---|---|---|
| 1 | 36 | F | MHNP | 7 | ++ |
| 1 | 46 | F | GP | 16 | ++ |
| 1 | 63 | F | MHNP | 5 | ++ |
| 1 | 46 | F | GP | 15 | + |
| 1 | 65 | M | MHNP | 10 | ++ |
| 1 | 46 | M | GP | 15 | ++ |
| 1 | 49 | F | GP | 14 | ++ |
| 2 | 39 | F | GP | 1 | +++ |
| 2 | 37 | F | GP | 5 | + |
| 2 | 35 | F | GP | 4 | ++ |
| 2 | 36 | F | GP | 3 | ++ |
| 2 | 40 | F | GP | 5 | ++ |
| 3 | 62 | F | MHNP | 18 | ++ |
| 3 | 36 | F | MHNP | 3 | +++ |
| 3 | 52 | F | MHNP | 11 | + |
| 3 | 56 | F | MHNP | 8 | +++ |
| 3 | 58 | F | MHNP | 8 | + |
| 3 | 55 | F | MHNP | 9 | + |
| 4 | 45 | F | GP | 21 | + |
| 4 | 32 | M | GP | 3 | ++ |
| 4 | 45 | F | GP | 17 | ++ |
| 4 | 31 | M | GP | 2 | + |
| 4 | 56 | M | GP | 22 | ++ |
| 4 | 53 | M | GP | 20 | ++ |
| 4 | 34 | M | GP | 7 | + |

**Table 6.1.** continued

| Nº Focus group[a] | Age (years) | Sex[b] | GP/MHNP[c] | Work experience (years) | Experience with patients with MID[d] |
|---|---|---|---|---|---|
| **4** | 58 | F | GP | 28 | + |
| **4** | 34 | F | GP | 5 | + |
| **4** | 29 | M | GP | 1 | + |

[a] Focus groups 1, 2, 4 were held live, focus group 3 online;.[b] F: Female, M: Male; [c] GP: General practitioner, MHNP: Mental health nurse practitioner; [d] - None, + low, ++ average, +++ above average of experience with patients with mild intellectual disabilities.

**Box 6.1.** Themes reflecting the complexity of primary mental health (MH) care provision to adults with mild intellectual disabilities (MID) from the perspective of general practitioners (GPs) and mental health nurse practitioners (MHNPs)[a]

**Theme 1: GPs' and MHNPs' struggles with adapting to challenging patient characteristics**

- Patients' reason for encounter is often unclear or difficult to discern
- Multiple simultaneous problems, medical and non-medical
- Patients are easily disoriented when facing problems
- Standard guidelines for diagnosis and treatment are often not applicable to patients with MID
- Patients struggle with practical implementation of practitioners' advices and organisation of care
- The MID often goes unrecognised or is not addressed

**Theme 2: Importance and difficulties of establishing a good doctor–patient relationship**

- May be complicated by the vast difference between the lived experiences of practitioners and patient
- May be influenced by patient's previous negative experiences in care or support
- A paternalistic stance on decision making is often adopted in the doctor–patient relationship

**Theme 3: Facilitating and hampering roles of the patient's network**

- A supporting formal or informal network can assist both practitioners and patients; however, it is not always available or lacks of continuity
- The network can contribute to the complexity of MH problems
- The network may often not provide the patient with the necessary emotional and practical support

**Theme 4: GPs' and MHNPs' challenges to provide care in the healthcare chain**

***Finding appropriate care and support***

- The practitioners' regular network is inadequate, and there is a lack of specific networks for patients with MID
- There are regional differences in the organisation of care and support for patients with MID
- It is often unclear for practitioners how additional care and support is reimbursed
- It is often unclear for GPs where to request a formal IQ test and how it is reimbursed
- MID is often an exclusion criterion for secondary MH care
- Support and treatment in secondary care lack alignment with the MID
- Long waiting times for additional support and care

***Collaboration in the healthcare chain***

- There are often multiple professionals involved around a patient, with lack of communication, coordination, and alignment between these professionals
- Roles and responsibilities are not clear to practitioners, other involved professionals, and patients
- There is lack of MID knowledge within the healthcare chain

[a] For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified

### *Theme 1: GPs' and MHNPs' struggles with adapting to challenging patient characteristics*

Participants indicated that patients with both MID and MH problems often present with multiple problems, medical and non-medical, simultaneously and that these patients easily become disoriented when facing problems, manifesting in anxiety, stress, and somatic symptoms. Partly because of these aspects, this patient group frequently consults the GP.

Their reason for encounter is often unclear or difficult to discern. Patients do not explicitly request help, have a multitude of requests, or the stated request does not align with the underlying problem.

> *They always have a lot of problems...'What are you actually here for, what was the question?' 'Oh yes', as if they completely forgot... then it's very difficult to go in a certain direction. (F3, MHNP)*

This causes practitioners to spend a considerable amount of time clarifying the help request, untangling the multitude of problems, maintaining structure in the consultation, prioritising, and devising a plan of action.

Participants experience that this patient group generally requires a different approach for diagnosis and treatment than described in the standard MH guidelines, as patients' abilities and circumstances often render these not directly applicable. Deviating from these guidelines and applying a suitable approach requires the practitioner to have specific knowledge and experience, which is often lacking, as stated by this participant:

> *As a young healthcare provider, you're still quite focused on yourself and cling to guidelines and protocols, but with this target group...those don't really apply anymore, and you find yourself in a kind of swamp, and you just have to deal with it. (F2, GP)*

Participants note that patients often appear to struggle with the practical implementation of given advice and with organising their own care. Consequently, patients often return to the GP with the same type of symptoms.

Participants consider themselves able to identify certain signs indicating (M)ID. However, acknowledge that they frequently miss MID in patients, resulting in overburdening the patient and initiating an inadequate MH trajectory because they do not adapt their approach to the MID.

> *Those [patients with MID] need to be recognised to receive the appropriate care. I wonder: who is going to do that? I think it's up to us [GPs] to identify them. (F4, GP)*

Moreover, when participants do signalise indicators of MID, discussing the possibility of MID with patients is found to be challenging as they do not always know how to approach it.

**Box 6.2.** Theme 1: GPs' and MHNPs' struggles with adapting to challenging patient characteristics Practice-based insights that participants in our study deemed to contribute positively to the quality of primary mental health (MH) care for adults with mild intellectual difficulties (MID)$^{a}$

**Improve knowledge, experience, and affinity with the patient group**

- Improve practitioners' confidence to rely on intuition, deviate from guidelines, and think outside the box by:
    - More focus on this patient group in (postgraduate) general practitioner (GP) training programmes
    - Easily accessible consultation with a colleague practitioner or ID physician who has knowledge and experience with this patient group

**Be attentive to the patient's need for additional support**

- Within the GP practice. For example: the GP accompanying the patient to the appointment desk to schedule a follow-up appointment and ensuring that the practice's website and practice are easily accessible for people with MID
- Outside the GP practice. For example: the practitioner looks up bus times with the patient, so that the patient can attend an MH service intake appointment on time

**Timely identification of MID in patients**

- Improve practitioner knowledge and experience in identifying MID
- Develop practitioner-applicable tools for assessment and for discussing the suspicion of MID with the patient
- Early identification of MID by teachers, paediatricians, and public health professionals
- Clear information for practitioners on where to request a formal IQ test and how it can be reimbursed
- Registration of MID in the medical record through an episode, memo, or attention note
- Share knowledge of a confirmed or suspected MID with relevant parties in the healthcare chain

[a] For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified

### *Theme 2: Importance and difficulties of establishing a good doctor–patient relationship*

Participants saw a good and sustainable relationship as particularly relevant for this patient group. Knowledge about the patient's context and lived experiences can aid in assessing symptoms and patients' follow-up of practitioner advice. Participants indicated that their necessary extra investment in building a relationship with these patients might be complicated by the vast difference between the lived experiences of a patient with MID and a practitioner, as one GP remarked:

> *...you have to understand more about how the other person is because it's further away from you. That, I think, is really the crux, and that's why building that relationship takes more time and also requires more time to ultimately provide good care for mental health complaints. (F2, GP)*

Additionally, patients may have had negative experiences with care professionals in the past, challenging the establishment of a good relationship even more.

In general, participants indicated that, in the relationship with the patient, they often adopted a paternalistic stance regarding decision making, while aware that this limited the patient's choices. They found it difficult to assess the extent to which the patient could take responsibility in this regard and to determine their role as practitioner in this process.

> *It's also a difficult balancing act. I find it complicated, how much control do you give to the other person, when sometimes you just want to say, 'we're going to do this and this and this now because I see it's necessary', but at the same time, you don't want to completely override someone. (F4, GP)*

**Box 6.3.** Theme 2: Importance and difficulties of establishing a good doctor–patient relationship. Practice-based insights that participants in our study deemed to contribute positively to the quality of primary mental health (MH) care for adults with mild intellectual difficulties (MID)[a]

**Invest in the doctor–patient relationship**

- The practitioner adapts to the patient's communication level: using simple words, speaking at a slower pace, and providing frequent repetition
- The practitioner gives sufficient attention and time to the patient; for example, conducting longer consultations or engaging regularly in supportive consultations
- The practitioner provides a calm and structured environment during consultations
- A designated practitioner in the practice is assigned as the main point of contact and responsible for continuity of care
- The practitioner notes the MID and additional communication needs in the medical record so that everyone in the practice can take this into account when interacting with the patient

[a] For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified

### *Theme 3: Facilitating and hampering roles of the patient's network*

Some patients with MID have a formal and/or informal network that can provide support to both the practitioner and the patient. A supportive network provides the practitioner with valuable knowledge about the patient and contributes to stability in their lives in both the short and the long term. However, in the participants' experience, networks can also be part of, or contribute to, patients' problems, by amplifying patients' stress, underestimating or overestimating their symptoms, lacking sufficient knowledge or skills to provide appropriate support, or having unrealistic or unspoken expectations of the practitioner.

> *And especially I think not getting caught up in the patient's panic [by carers], because that's often what I see. The patient notices that too, and then you enter a kind of circle...those problems worsen. (F2, GP)*

The absence of a network, or changes in individuals within the network, can create instability for the patient and affect MH problems negatively. Additionally, participants felt that the network did not always prioritise or have time for emotional support, whereas this group would benefit from that. Participants observed that, despite the presence of a network, patients continued to rely on practitioners for supportive consultations and that patients did not always feel heard by their network.

> *What you often see is that, for them [professional carers], it's more like, 'I help a bit with finances and administration, and I go to the supermarket with them', but it stops there, and then you're not addressing that aspect of MH support that this group specifically needs. (F4, GP)*

Participants saw cooperation with the network as valuable; however, it often requires extra time and effort for them to involve and inform persons in the network – time that is not always available.

> *What I always keep in mind is how important it is to involve the network, whether it's the personal network or the professional network, that it truly acts as a link. If you have a good understanding of that and can establish it well, I think this patient group will also rely much less on the GP.*
> (F4, GP)

**Box 6.4.** Theme 3: Facilitating and hampering roles of the patient's network. Practice-based insights that participants in our study deemed to contribute positively to the quality of primary mental health (MH) care for adults with mild intellectual difficulties (MID)[a]

- The practitioner actively involves the patient's network in the MH trajectory
- The practitioner recognises the capacity of the network and provides support, coaching, and psycho-education to the network regarding the patient's MH problems
- A stable network that provides long-term and consistent support to the patient, both practically and emotionally, is valuable for both the patient and the practitioner

[a] For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified

### *Theme 4: GPs' and MHNPs' challenges to provide care in the healthcare chain*

Participants emphasised that, in their practitioner role, they might not always be able to provide the care and support needed by patients with both MID and MH problems, especially when the problems were non-medical in nature or required expertise in MH care. Participants were convinced that timely access to appropriate support and care could limit MH problems and reduce the high demand for services in primary care practices. One participant felt isolated in providing care:

> *Then I'm treating, and I think: I'm here on my own again, but there should be much more happening in the home situation. (F4, GP)*

#### *Finding appropriate care and support*

Practitioners felt responsible for organising the necessary care and support for patients, as patients or their network might not be able to do so independently. This additional organisation, coordination, and mediation of care and support required extra effort and time. Challenges mentioned included the participants' regular network being insufficient, lack of a regional specialised network for this patient group or frequent changes within this network, and regional differences in the organisation of care. Especially regarding context-related problems where solutions lie outside the medical domain, the participants were often not aware how and where the appropriate support was available for their patients. In addition, issues and uncertainties regarding reimbursement could hinder the organisation of care and support.

> *Everyone is also concerned about whether it fits into that box, whether there's adequate reimbursement. (F3, MHNP)*

Participants often experienced confusion about where to request a formal IQ test and how it should be funded. A low IQ, or the absence of an IQ test, could be an exclusion criterion for specialised care, potentially denying patients access to treatments and expertise from which they could benefit. Additionally, available care or support did not always adequately align with the needs of individuals with MID, leading to patients being referred back to the GP if they could not articulate their needs or did not benefit sufficiently from the treatment provided.

> *And they [MH services] have a limit for the IQ, and if they say, 'you have an IQ below 75, goodbye, we're not going to start with that, figure it out yourself'. (F2, GP)*

Waiting times for MH services are often long, and significant bureaucracy in referrals is reported. For these reasons, participants felt that sometimes the maximum achievable outcome was to continue monitoring patients themselves, without the possibility of involving external professionals.

### *Collaboration in the healthcare chain*

Often, multiple professionals are involved in the care for this patient group. Regularly, there is a lack of coordination among these providers, as patients and their network may not be able to fulfil this role. Practitioners in this study often assumed the coordination role but faced challenges, as other care professionals might not be easily accessible, changed frequently, lacked adequate feedback mechanisms, and might be uncertain about roles and responsibilities. Lack of knowledge about MID among professionals involved was also an issue. When an MH trajectory is not functioning as intended, the GP is often the first point of contact for both the patient and other involved professionals. This may lead to feelings of irritation, as experienced by this participant:

> *If there's any irritation on my part, it's indeed more often in communication with other care professionals than with the client...there's still often a feeling of separation where you're trying to toss something over instead of actively working together. (F2, GP)*

**Box 6.5.** Theme 4: GPs' and MHNPs' challenges to provide care in the healthcare chain. Practice-based insights that participants in our study deemed to contribute positively to the quality of primary mental health (MH) care for adults with mild intellectual difficulties (MID)[a]

**Finding appropriate care and support**

- A clear and up-to-date overview for practitioners of the regional network for care and support to patients with both an intellectual difficulty (ID) and MH problems
- The professionals within the network are easily accessible for the practitioner, with clear lines of communication and the possibility of personal contact
- Sufficient capacity and MID knowledge within support and care services, including the availability of long-term support
- The GPs are supported by MHNPs or professionals in the public health or social domain for the organisation and coordination of care for this patient group

**Collaboration in the healthcare chain**

- The involved professionals around a patient are easily accessibility for patients, practitioners, and other professionals involved
- Consistency in individual care professionals involved in the patient's care
- Clear communication of tasks and responsibilities with all stakeholders, including the patient
- Low-threshold opportunities for GPs to consult a psychiatrist, ID physician, or members of the community team
- A regular transfer of patient information and knowledge between involved care professionals
- Knowledge about implications of MID throughout the healthcare chain

[a] For readability, the term practitioner is used for both GPs and MHNPs; when relevant, GP or MHNP is specified

## Discussion

In this study, we explored GPs' and MHNPs' experiences, needs, and recommendations for improvement regarding primary MH care. Participants perceived their patients with both MID and MH problems as complex cases. This related to patient factors, challenges experienced in the doctor–patient relationship, the presence and capacity of the patient's network, and orchestrating care in the healthcare chain. As a result, participants found it difficult to provide the appropriate care and that patients relied substantially on their GP, even for problems of a non-medical nature. These difficulties were often experienced as a burden. Practitioners believed that, if this patient group received appropriate care and support from the (in)formal network, practitioners, and other care professionals, MH problems might be limited at an early stage, the work pressure on primary care practices would decrease, and more intensive forms of MH care could, in some cases, be prevented.

## Strengths and limitations

This study has several strengths. Firstly, the focus groups were guided by a topic guide based on four themes that emerged from a previous interview study among patients with MID who received primary MH care. This topic guide was critically scrutinised by both the research team and the study's advisory group to ensure that practitioners' perspectives were collected as completely and broadly as possible. By integrating the perspectives of those who received and those who provided the care, valuable information was retrieved to inform research, practice, and policy about opportunities to improve primary MH care for people with MID. Secondly, participants had varying degrees of experience with the patient group and were reasonably equally distributed across the Netherlands. Finally, the focus groups were moderated by a trained researcher who, as an ID physician, could easily relate to the participants' clinical experiences, thereby adding to the depth of the discussion.

The main limitation of this study is that the practitioners' perspectives may be partly determined by the Dutch primary care model, reducing external validity. However, various countries have comparative primary care models, rendering the suggested implications for research and practice also valuable and applicable outside the Netherlands. Furthermore, in countries with weaker formal primary care systems, professionals working in non-institutionalised settings with people with both MID and MH will experience many of the problems described here.

## Comparison with existing literature

Our findings show some similarities with previous qualitative studies focusing on people with MH problems and a wider range of ID than MID. [1,

[15] However, in contrast to our study, concrete suggestions to improve care were scarcely provided in those studies. Only one study of which we are aware focuses on GPs' views on primary MH care for people with ID. [1] In that interview study, GPs also experienced problems in referring patients, and, as in our study, they described knowledge of the patients' background, continuity in the GP–patient relationship, and interdisciplinary meetings as helpful in providing optimal care.

Our results also resemble those of a systematic qualitative review study that focused on general MH care for people with ID by a broad range of MH care professionals, including GPs, psychiatrists, psychologists, therapists, and nurses. [15] That study also described the complexity of patient problem presentation and high service demands, the extensive carer resources and time required, and the emotional effects (e.g., feeling alone) on care professionals.

### Implications for research and practice

Several opportunities that may improve care were revealed and are elaborated on in the following. Firstly, recognising and establishing MID in patients, and taking into account the MID throughout the MH trajectory, is of upmost importance. [16] This is preferably done as early as possible in a person's life and not solely as a task of a GP, but also of teachers, paediatricians, and social care professionals in the public health domain. This means that it is important to invest in training programmes on MID recognition not only for GPs, but also for other professionals who may encounter this patient group. Those training programmes should focus on screening tools for MID, for example SCIL and HASI, [17, 18] and also on conversational techniques on how to discuss a suspected MID with a patient. When a formal IQ test is required, this test should be easily accessible, with clarity about local test locations and financing.

Secondly, on the GP-practice organisational level, two aspects will contribute to a good, sustainable doctor–patient relationship: (1) optimal continuity in care provided in the practice by the same person [19]; (2) registering the MID and additional communication needs in the patient's file. This can act as a reminder for the practitioner's assistant to schedule extra time for a consultation, thus allowing the practitioner to give sufficient attention and time to the patient during consultations and adapt the level of communication to the MID. From an earlier study, it appears that more than 80% of people with MID were not registered as such in Dutch primary care.[5] In the United Kingdom (UK), registration is higher thanks to the register for people with ID developed for the Quality and Outcomes Framework, an incentive programme for all GP practices in the UK. [20] However, there too, there are people with MID who are not registered as such in primary care. [21]

Thirdly, practitioners need to actively involve the patient's network. Regarding the informal network, it is important for practitioners to be aware of the network's capacity and signalise if additional support for the network or patient is needed. [22] A strong formal network consists of familiar professionals who are able to provide both practical and emotional support to people with MID, for whom it is clear what their practitioners and carers expect of them. [23] Therefore, it is important that these professionals have adequate training and peer supervision opportunities, with clear tasks and an appropriate workload. [24]

Fourthly, because patients with both MID and MH problems often present with multiple problems that are often not within the practitioner's scope, the practitioner must have access to an adequate regional network of both medical and non-medical professionals who work closely and in coordination. The findability and accessibility of these professionals are not always evident for Dutch practitioners. In contrast to the UK and the United States of America, in the Netherlands there are no ID psychiatrists, Community Learning Disability Teams, or ID nurses available to support practitioners in the care for this patient group. [25-27] These professionals play a role in coordinating care, improving individuals' physical and mental health, reducing barriers to independent living, supporting individuals in leading a fulfilling life, and advocating strongly for improved knowledge about the care for patients with ID in general. The experiences gained internationally can provide insights into whether and how the introduction of an ID nurse would be of added value in Dutch primary care practices.

Finally, interprofessional collaboration is more effective when there is adequate reimbursement, a team vision, shared goals, formal quality processes, and shared information systems.[28, 29]

## Conclusion

Practitioners perceive patients with both MID and MH problems as complex patients who present with multiple problems simultaneously, medical and non-medical, and continue to rely on them, even if the problems are non-medical in nature. Consequently, practitioners often experience providing care and support to this patient group as burdensome. In order to provide effective primary MH care, it is important for practitioners and the other professionals involved to invest in a strong relationship with the patient, consider MID throughout the MH trajectory, and establish a stable and sustainable support network and coordinated collaborative care around the patient. Organising effective care and support may improve the quality of primary MH care, decrease the pressure on primary care practices, and, in some cases, prevent more intensive forms of MH care.

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# Supplementary

**Table 6.1.** Topic guide for study

| Topic[a] | Main questions |
|---|---|
| Cumulative vulnerability | Can you recall a patient or patients with mild intellectual disabilities (MID) whom you have seen in the recent period with mental health (MH) problems?<br>What memory comes to mind when you think about this? |
| Needs regarding the GP | Do you experience a difference in the help requests from patients with both MID and MH problems compared with patients without intellectual disabilities (ID)? Can you say more about this?<br>Do you experience a difference in the care you provide to patients with both MID and MH problems compared with patients without ID?<br>Can you say more about this? |
| Needs regarding the network | What are your experiences with the role of the network for patients with both MID and MH problems, and what does this evoke for you? |
| Self-determination | In today's society, personal responsibility and autonomy are important. If you consider the patient again and think about 'responsibility' and self-determination, what does this evoke for you? |

[a] The topics are based on four themes that emerged from a previous interview study among patients with MID who received primary MH care. [8]

# Chapter 7

# General discussion

In my general introduction, I introduced you to Bob, an illustrative patient from my medical practice as intellectual disability (ID) physician. Bob is a man with mild intellectual disability (MID) who had been suffering from mental health (MH) problems for most of his life. For an extended period, he did not receive the treatment and support that he needed, resulting in an increase in both MH and social problems. It was patients like Bob who made me wonder what would have happened if such a person had received the appropriate (MH) care and support at an earlier stage in his life and motivated me to write this thesis. As Desmond Tutu said:

> *There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in.*

The aim of this thesis was to provide insight into quantitative and qualitative characteristics of MH care for people with MID, with a main focus on the primary care setting, to provide guidance to improve MH care for people with MID, preferably upstream and through primary care. In this chapter, I reflect on the results from the different studies and consider the implications of our findings for practice, policy, and research in order to improve MH care for people with MID.

## Characteristics of patients with both MID and MH problems

During my PhD journey, it became clear to me not only that patients like Bob are illustrative of patients in my specialized medical practice as an ID physician, but also that his life course is common for people with MID in general. This makes them a group of patients whom general practitioners (GPs) often encounter in their practice. The findings of this thesis show that patients with both MID and MH problems have particular characteristics that impact the course of their MH trajectory and their lives. Below, I discuss these characteristics, using Bob's story as an example, thereby providing insight into the patient group that is the focus of this thesis (Box 7.1).

Compared with people with no ID, people with MID are likely to experience MH problems and encounter GPs or MH services at a much younger age (**Chapters 3 and 4**). Bob too developed MH problems at an early age (17 years), with considerable impact on the rest of his life.

GPs and mental health nurse practitioners (MHNPs) characterize people with both MID and MH as patients with multiple problems, both medical and non-medical, present at the same time. According to GPs and MHNPS, these multi-problems often need to be addressed simultaneously and contribute to the difficulties that they experience in providing and organizing the appropriate care and support for this patient group (**Chapter 6**). Bob also experienced problems in several life domains, often in the same period: depression, loneliness, financial debts, no stable work, substance use. This accumulation of problems worsened Bob's situation over time.

Sustainable formal and informal patients' networks can play an important supportive role in the MH trajectory for patients with MID, but also for GPs and MHNPs (**Chapters 2, 5, and 6**). In Bob's case, he was able to thrive and develop in the presence of a supportive network of formal caregivers from the age of 25, after a long period of absence of support from family and friends when he was living on his own.

Signs of undertreatment of people with MID in advanced MH services, particularly when the MID is not registered as such, were revealed by our population-based MH service database study. This is reflected in shorter trajectories and fewer treatment and diagnostic activities compared with patients with no ID, in these services. Disturbingly, patients with MID need more crisis interventions and MH hospital admissions (**Chapter 4**). In addition, in both primary care and specialized MH care, there is a high prevalence of unspecified MH diagnoses that may indicate that professionals struggle with establishing the appropriate MH diagnosis and associated suitable treatment for patients with MID (**Chapters 2 and 3**). Bob clearly did not benefit from the treatment in MH services, as reflected in his multiple re-admissions, which may have resulted in his being seen as an unmotivated patient who did not adhere to therapy, according to care professionals.

Our studies indicate that MIDs are often missed by care professionals. In primary care 80%, and in MH services 61%, of patients with MID have no registration of their ID in their medical file (**Chapters 3 and 4**). GPs confirm that they often do not recognize MID and realize that they are at risk of providing care and support that does not meet the patient's needs (**Chapter 6**). It was not until Bob was 25 years old that his MID was diagnosed. Before, many care professionals were involved, but he had never been tested for MID. For Bob, the establishment of MID was a tipping point, as he then was provided with more appropriate care and support.

Unfortunately, Bob's story does not include information about GPs' role regarding his MH problems over the years. However, from our studies, it is clear that GPs play a key role in the MH care for patients with MID (**Chapters 2, 5, and 6**). This patient group puts a high demand on GPs, reflected in a higher prevalence of MH problems among MID patients and more consultations and types of prescriptions compared with patients with no ID or with MID alone (**Chapter 3**). GPs' and MHNPs' difficulty in providing and coordinating appropriate care and support for this patient group may lead to feelings of insecurity and frustration (**Chapter 6**). In addition, patients often feel vulnerable in primary care, instigated by their MID and reinforced by MH problems. This results in additional expectations and needs regarding their GP, MHNP, and network on a cognitive, practical, or emotional level (**Chapter 5**).

**Box 7.1** Characteristics of patients with both mild intellectual disabilities and mental health problems based on our findings

- Experiencing mental health (MH) problems at a relatively young age
- Presenting with multi-problems in primary care, both medical and non-medical, which often need to be addressed simultaneously
- Needing a supportive informal and/or formal network
- Showing signs of being undertreated in advanced MH services
- Experiencing more crisis interventions and MH hospital admissions
- Their mild intellectual disabilities are often missed by involved care professionals
- Their general practitioners (GPs) often play a key role in providing and organizing care and support but find it difficult to fulfil this role satisfactorily
- Putting a high demand on their GPs, reflected in high number of consultations and types of prescriptions
- Feeling vulnerable in primary care because of their mild intellectual disabilities, reinforced by their MH problems
- Having additional expectations and needs regarding their GP, MH nurse practitioner, and network

## Five upstream opportunities to improve MH care for patients with both MID and MH problems

In addition to the overview of the characteristics of patients with both MID and MH problems, this thesis contributes to insights into several opportunities upstream to improve primary (MH) care and support for this extra-vulnerable patient group. I highlight and elaborate five opportunities that emerged throughout the studies, combined with my personal experiences as an ID physician. These opportunities align with GPs' core values (Person-centred, Continuous, Collaborative care, Medical generalist) established by the leading national Dutch general practitioners organizations in 2019[1] and indicate the focus points that can be derived from these core values for this specific patient group. The five opportunities are:

- Early recognition and acknowledgement of MID in patients
- Continuity of care
- The supportive role of the patient's (in)formal network
- Combine knowledge and experience
- Domain-transcending collaborative care

I elaborate further on each opportunity from a practical perspective in the Dutch context, providing recommendations on: What practitioners can do, What practitioners' and patients' networks can do, What health policymakers can do, and What researchers can do. Boxes 7.2–7.6 provide overviews of these recommendations for each opportunity, based on findings in our studies, (inter)national literature, and my personal experiences as ID physician. For the sake of readability, practitioner is stated where it applies to both GPs and MHNPs. When necessary, GP or MHNP is specified.

## Early recognition and acknowledgement of MID in patients

### The importance of recognition and acknowledgement of MID for person-centred care

From my perspective, early recognition and acknowledgement of MID is an essential prerequisite for delivering person-centred care to patients with MID in general practice. Person-centred care is defined as care that is tailored to someone's personal needs, desires, and preferences, with the aim of the person leading a meaningful life. This includes: a two-way interaction between the practitioner and the patient where information is conveyed and shared, a respectful and empathetic practitioner attitude with attention on the patient's individual needs and perspective on care, and the patient's active involvement in the care and decision-making process. [1, 2] Person-centred care in vulnerable patient groups has positive effects on (MH) healthcare outcomes, patient involvement, and patient and practitioner satisfaction, and results in fewer consultations, referrals, and hospital admissions. [3] Effective communication is one of the most important identified underlying mechanisms for effective person-centred care in vulnerable patients. This means that the practitioner uses easy-to-understand words, is empathetic, listens attentively, and checks whether the patient understands everything. [3] For patients with MID, it is therefore important for practitioners to recognize MID so that they can adapt the communication to the patient's abilities. Patients with both MID and MH problems often face extra communication difficulties arising from the MH problems, in addition to their MID. They emphasize that the use of simple or supportive communication is helpful for effective information transfer and implementing their practitioner's advices in their daily lives (**Chapter 5**).[4]

### The practitioner struggles with MID recognition

The majority of practitioners consider it both important and their responsibility to identify MID in patients. However, they find recognition of MID highly challenging (**Chapter 6**). [5] We also observed this in our quantitative study, where we found that in primary care the presence of MID is recorded in only 20% of patients (**Chapter 3**). The most commonly mentioned barriers include insufficient education on the topic during their GP training and a lack of information about MID in their postgraduate education. Only few GPs are familiar with screening tools or guidelines related to the identification of an MID, and even fewer apply these (**Chapter 6**).[6]

Another notable aspect is that the majority of participating GPs feel reluctant to address the presumption of an MID. They are concerned about harming the doctor–patient relationship or stigmatizing patients (**Chapter 6**). [6] It may be questioned whether this reluctance is justified; in my own medical practice, I have spoken with patients, including Bob, who expressed a sense of relief when a practitioner finally mentioned the possibility of MID. This provided them insight into why they kept encountering a number of problems in their lives. In addition, participants in the patient-interview study expressed feelings of shame when they had to repeatedly admit that they did not understand the given information and preferred the practitioner to be aware of their MID and to take this automatically into consideration during consultations (**Chapter 5**). The struggles for both practitioners and patients in addressing a topic like MID are also evident in other sensitive issues, such as substance use, low literacy, and domestic violence.[7-9] Practitioners often feel uncomfortable initiating a conversation about these issues; it is not a standard question in a consultation where the patient often has another reason for encounter, and practitioners have a lack of knowledge and experience on these issues and may not know how to address them neutrally.[8] Patients with MID themselves are also reluctant to bring up such sensitive issues, whether out of shame, lack of awareness of an underlying problem or of the impact of the issue on their health, or erroneously assume that the practitioner is aware of it.[7, 9] The use of open, non-judgmental questions within a trusted doctor–patient relationship is seen as helpful in addressing this sensitive issue.[7-9] It would be worthwhile to gain insight, through qualitative research, into the experiences and needs of patients when practitioners are addressing potential MID. This information could be used for the development of guidelines and practitioners' training programmes that address this topic.

Of course, the responsibility for early recognition of MID does not lie solely with GPs, but also with other care professionals in the GPs' and patients' networks, who may encounter these patients at an earlier stage or more often than a practitioner. This includes professionals in youth healthcare, the social domain, and MH services. It is also important for these professionals to be able to recognize signs of MID, to use screening tools,[10, 11] and to address the presumption of an MID with the person. Our research shows that, in MH services, patients' MID often goes unnoticed. Given the high prevalence of MID among patients in MH services, it is recommended to routinely screen for MID during intake assessments (**Chapter 4**).[12] When

MID is identified, it is crucial that this information, with the patient's consent, is shared with other involved professionals.

### An IQ test, not as simple as you think

In the case of a strong suspicion of MID, the practitioner can refer the patient for an IQ test. It can be helpful to request an IQ test including a psychodiagnostics assessment. This assessment ensures that, in addition to the overall IQ score, specific needs across different areas of skills (language, practical skills, emotional, processing speed, and so on) are assessed and identified. In the context of person-centred care, having a comprehensive understanding of the patient's abilities allows the practitioner to tailor care and support optimally to the individual patient. Additionally, an IQ test is sometimes mandatory before referring a patient to specialized ID services. However, for GPs, it is not always clear where an IQ test can be administered and how it is reimbursed, resulting in prolonged uncertainty at times, potentially denying patients the right care and support (**Chapter 6**).

To facilitate referral for an IQ test, a regionally up-to-date overview of organisations accessible for the practitioner is needed. A logical place could be the ZorgDomein referral e-module,[13] where Dutch GPs are accustomed to request various diagnostic examinations. However, an IQ test is often not offered as a stand-alone diagnostic examination in the medical domain and thus falls outside the ZorgDomein referral module. This may be because an IQ test is reimbursed by basic health insurance only if it is part of a treatment package.[14] I find this hard to comprehend, given that an IQ test is a prerequisite for person-centred care and moreover needed to access more specialized forms of (MH) care before any treatment can be started. Full reimbursement of an IQ test, including psychodiagnostics assessment, by basic health insurance is therefore needed and can potentially reduce healthcare costs, as it may ensure that patients receive more appropriate care and support.

### Adequate registration of MID in the medical file

Once the MID is established, it is important that practitioners register the MID in a nuanced and standardized way in the patient's medical file.

This ensures that the presence of MID becomes known to GP assistants, locum GPs, and professionals to whom referrals are made (**Chapters 5 and 6**).[6] Preferably, not only the presence of MID, but also the additional communication and support needs for this specific patient should be registered and communicated. Most people with an MID do not mind if their ID is registered in the medical record and shared with other professionals during a referral (**Chapter 5**).[5]

Although practitioners acknowledge the benefits of MID registration, it is still done to just a limited extent in primary care, both internationally and nationally (**Chapter 3**).[15] In the UK, it is estimated that 75% of patients with ID in primary care are not registered as such, mostly people with MID.[15] This is even despite a financial incentive from the government that provides practitioners with additional compensation when they have registered patients with ID in their practice. The reasons in the UK for this high percentage are unclear coding, the use of different ID definitions, and patients not having an official diagnosis.[15] Therefore, in 2019, the National Health Service (NHS) established a guideline to enhance the identification of individuals with intellectual disabilities in general practices.[16]

In the Netherlands, there are no uniform agreements on whether and how a practitioner should register MID in the medical record. As a result, this registration occurs in various inconsistent ways (**Chapter 3**):[6] in the episode list, in a note, or with an International Classification for Primary Care (ICPC) code, of which version 2 is currently mostly used by Dutch GPs.[17] The most commonly used ICPC code is P85, which stands for mental retardation. This code lacks nuances and is perceived as stigmatizing (**Chapter 3**).[6] In the newly developed ICPC version 3 there is, unlike version 2, the possibility to registrate functioning or function-related aspect of patients, including nuances in the level of ID and communication needs.[18] However, ICPC version 3 needs to be further implemented in GP practices, and agreements should be made regarding a consistent method of MID registration.

**Box 7.2.** Recommendations to improve or implement early recognition and acknowledgement of mild intellectual disabilities in patients in primary care

**What practitioners can do**

- Follow training programmes on:
    - How to recognize signals that indicate mild intellectual disability (MID)
    - The use of MID screening tools
    - Conversational techniques on how to discuss a suspicion of MID with a patient
    - How to effectively communicate with patients with MID
- Train practitioners' support staff on how to effectively communicate with patients with MID
- Implement the use of MID screening tools in daily practice
- Refer patients for an IQ test including psychodiagnostics assessment to identify their needs across different areas of skills
- Register patient's MID and additional communication and support needs in the patient's medical file, in a consistent manner
- Communicate identified MID to other involved professionals, with the patient's consent

**What practitioners' and patients' networks can do**

- Professionals outside the general practitioner (GP) practice who come into contact with people with MID should also be adequately equipped to recognize MID, use MID screening tools, and address a suspicion of MID with the person
- Routinely screen for (M)ID in mental health services during intake assessments
- Share identified MID with other involved professionals, with the patient's consent

**What health policymakers can do**

- Incentivize the incorporation of intellectual disabilities modules in GP training and postgraduate training
- Provide an up-to-date regional overview of where an IQ test can be administered
- Fully reimburse an IQ test, including psychodiagnostics assessment, by basic health insurance
- Support development of a GP guideline on recognition, screening, addressing, diagnosing, acknowledging, and registering (M)ID in their patients
- Further implement the International Classification for Primary Care version 3 in GP practices

**What researchers can do**

- Gain further insight into patients' experiences and needs regarding practitioners addressing potential MID

# Continuity of care

## The benefits of continuity of care

Continuity of care is expected to have a positive effect on both the primary MH trajectory and the MH outcome for patients with MID. Continuity of care is one of the core values in primary care[1] and includes longitudinal and relational continuity of care. [19] Longitudinal continuity involves the long-term relationship between the primary care provider and the patient, beyond specific episodes of illness. Relational continuity refers to the quality of the longitudinal relationship between the practitioner and the patient, in term of accommodating patients' needs and preferences, such as communication and respect for patients.[19] Reported benefits of continuity of care include a better doctor–patient relationship, better preventive care, fewer hospital admissions, reduced healthcare costs, and improved patient satisfaction.[19, 20] In studies that focus on primary care to people with ID in general, the importance of continuity of care is also emphasized.[21, 22] The patients in our interview study expressed the importance of GPs having an understanding of their context, life story, and communication needs (**Chapter 5**). Both patients and GPs see a strong continuous doctor–patient relationship as a key element for this (**Chapters 5 and 6**).

### Continuity is jeopardized at various levels

In daily practice, a practitioner's longitudinal and relational continuity of care is not always evident (**Chapter 5**) and is influenced at various levels: the practitioner, the GP practice, and the organization of healthcare. At the practitioner level, we know that certain practitioner character traits can contribute to the quality of the relationship between the primary care provider and the patient. Valued behavioural skills for establishing a quality relationship (confident, empathetic, humane, personal, forthright, respectful, and thorough)[23] may be challenged in situations dealing with patients with both MID and MH problems, as the care for this patient group can lead to uncertainty and frustration among practitioners (**Chapter 6**). In addition, practitioners indicate that there is a vast difference between the lived experiences of a patient with MID and a GP, posing a barrier to mutual understanding. Furthermore, patients often have had negative experiences with care professionals in the past. Therefore, building a trustful relationship takes more time and effort with patients with MID than with patients with no ID (**Chapter 6**). The practitioner adapting the communication level and paying attention to adequate information transfer is supportive in improving the quality of the relationship with patients with (M)ID.[24]

At the GP practice level, it is important to meet patients' and practitioners' frequently articulated needs for extra time and attention to build a trustful doctor–patient relationship (**Chapters 5 and 6**). Planning for double consultation time and room for regular follow-up consultations can make a significant contribution to meeting these needs. [21] Practitioners' support staff can be reminded of this by adequate registration of MID and additional needs in patients' medical files. To ensure longitudinal continuity, it is desirable for the same practitioner to provide care over time. According to GPs themselves, this is most feasible in small, stable, and familiar teams with two to three usual GPs who share the workload and cover each other's absences. [20]

At the organization of healthcare level, some concerning developments in the Netherlands are putting continuity in primary care under pressure. These include an increasing workload in primary care, a reduction in permanent GPs and support staff, and rising expectations from the government, the healthcare domain, and the general population about the accessibility and possibilities of primary healthcare. [25] Without intervention, vulnerable patients for whom continuity of care is of extra importance, like patients with MID and MH problems, will be the first to suffer the consequences. Policymakers should invest in collaboration with healthcare insurers, care professionals, and citizens to secure the sustainability of high-quality, accessible, and affordable primary care.

### Can task substitution contribute to the continuity of care?

Participants in the interview study indicated that longitudinal and relational continuity of care was in some cases easier to achieve with the MHNP rather than with the GP. Patients perceive MHNPs as having more time and giving more attention and as less formal than GPs (**Chapter 5**). However, an MHNP is focused mainly on MH problems and may not always have experience and affinity with individuals with (M)ID (**Chapter 6**). This makes me wonder whether the introduction of a new type of nurse practitioner, the ID nurse practitioner (ID-NP), with expertise in the extra communication and domain-transcending needs of patients with MID, could be of added value in primary care practice. This follows the example of ID nurses already working in the United Kingdom and the United States of America. [26, 27] In these countries, these nurses play a role in improving individuals' physical and MH, reducing barriers to independent living, supporting individuals in leading a fulfilling life, and are strong advocates in fostering improved knowledge about the care of patients with ID in general. They operate in various settings, including community centres, schools, primary care, and hospitals, often as part of multidisciplinary teams. This substitution also builds on the experience established in Dutch primary care with special elderly care nurse practitioners, who are present in nearly half of general practices[28] and provide integrative person-centred care in cooperation with care professionals inside and outside the primary care practice. [29] Just like people with MID, the elderly are often extra vulnerable patients who present themselves with multi-problems in more than one life domain, need continuity and monitoring, and have several different care professionals involved. An ID-NP could work locally or regionally in primary care practices to support practitioners and organize and provide continuity of care to patients with all levels of ID. The experiences gained internationally, along with Dutch elderly care NPs, can provide insights into whether and how an ID-NP would be of added value in primary practices, both for continuity of care and the domain-transcending organization of care (see also the opportunity: 'Domain-transcending collaborative care').

**Box 7.3.** Recommendations to improve continuity of care

**What practitioners can do**

- Invest extra time and effort in establishing a trustful practitioner–patient relationship
- Book double consultation with the regular practitioner; adequate registration of mild intellectual disabilities in the medical file can be a reminder for the support staff to do so
- Acquire skills and use existing tools for appropriate communication and information transfer
- Schedule regular follow-up consultations
- Work in small, stable, and familiar primary care teams with two to three regular general practitioners

**What practitioners' and patients' networks can do**

- Ensure longitudinal and relational continuity in practitioners' and patients' networks (see also Box 7.4)

**What health policymakers can do**

- Further invest in high-quality, accessible, and affordable primary care for now and in the future

**What researchers can do**

- Conduct research on the added value of an intellectual disability nurse practitioner regarding the continuity of care

## The supportive role of patients’ (in)formal networks

### Collaboration with the patient’s network

Persons in the patient’s network can be supportive for both the practitioner and the patient with MID and MH problems and can therefore be important to collaborate with. They support the patient to access primary care when experiencing MH problems and help the patient and the GP with information transfer, decision making, and execution of the treatment and monitoring plan (**Chapters 2, 5, and 6**). Additionally, they provide support in other life domains, like household and work, when the patient experiences extra challenges because of MH problems. [30] The patient’s network can be informal, consisting of family and friends, and formal, consisting of professional caregivers from both the medical and the social domain, or both.

In the UK guideline ‘MH Problems in People With Learning Disabilities: Prevention, Assessment and Management’ and in the Canadian guideline ‘Primary care of adults with intellectual and developmental disabilities’, particular attention is paid to the involvement of the patient’s network in the (mental) healthcare for patients with ID. [31, 32] In the Netherlands, the importance of involving the patient’s network is emphasized in the MH care guideline for individuals with MID[33] and in support guidelines used in ID services. [34] These not only raises awareness, but also provides professionals with tools on how to involve the network in patient care. However, this aspect is currently lacking in the Dutch College of General Practitioners’ (NHG) guidelines on MH issues. Given that GPs often encounter patients with both MID and MH problems (**Chapter 3**) and that patients and GPs experience added value from an involved network (**Chapters 5 and 6**), it is worthwhile to include in the NHG guidelines the importance of the involvement of patients’ networks for this particular patient group.

### Strengthening patients’ networks

When persons from the patient’s network are involved, it is not self-evident that they have the capacity, knowledge, and experience to provide the support needed on a practical and/or emotional level (**Chapters 5 and 6**). Family members of people with both ID and MH problems reported the need for understandable information about their relatives' diagnosis and treatment, for help to develop skills to support their relative, and for the provision of support for themselves. [35] For caregivers from the formal network also, it is not always clear what their role is regarding the patient's (mental) healthcare, [36] and they are often mainly pedagogically trained with limited knowledge and skills regarding (mental) health problems. In my personal contacts with practitioners and professional carers, I have noticed that GPs sometimes overestimate the knowledge and skills of the individuals in the formal network, leading to miscommunication and inappropriate expectations on both sides. Although it is relevant for practitioners to pay attention to the capacity and knowledge of the network, it is also up to the individuals in the formal network to acquire sufficient training and peer supervision to support people with both MID and MH problems, and to communicate with the GP about what they can or cannot contribute.

The aforementioned UK guidelines include attention on support and interventions aimed specifically at the needs of persons in the network in order to ensure that patients with both MID and MH problems are supported adequately and sustainably. [31] Previous research in the Dutch setting has provided insight into actions and organizational factors that facilitate health information transfer and the role that the network can play in this. [37] However, it would be useful to gain additional insight into the specific needs of both the network and the practitioners regarding collaboration in care and support for patients with MID and MH problems. This information could also contribute to the further development of NHG guidelines and (interprofessional) training programmes for the network and practitioners, ensuring a better alignment with their needs.

When there is no adequate support network available, and it is deemed necessary, Dutch practitioners can refer to the municipalities where, through the Social Support Act (WMO), formal support can be sought for specific needs in the social domain, such as providing assistance with daily activities, addressing financial problems, and so on. Practitioners are not always aware of all the possibilities, partly because of local organizational differences, even though availing of them could relieve both the patient and the practitioner (**Chapter 6**).

The high level of discontinuity of caregivers in the formal network is a concern for practitioners, because this does not benefit the collaboration, including information exchange (**Chapter 6**).[38] This is also connected to the current shortage of healthcare professionals in the job market.[39] To provide longitudinal and relational continuity, it is important that professionals in the formal network of patients with MH problems and MID are retained.

**Box 7.4.** Recommendations to strengthen the supportive role of patients' (in)formal networks

**What practitioners can do**
- Determine the key persons in a patient's life and actively involve them in the mental health (MH) trajectory
- Clearly communicate expectations regarding the network
- Pay attention to the capacity and knowledge of the network and provide, or advise, additional support and training when needed
- Refer to the municipalities when (extra) formal support is needed in the social domain

**What practitioners' and patients' networks can do**
- Ensure that formal patients' networks acquire sufficient available training and peer supervision
- Become familiar with existing communication tools to support people with both mild intellectual disability (MID) and MH problems

**What health policymakers can do**
- Supplement the relevant Dutch College of General Practitioners' (NHG) guidelines with specific recommendations regarding involving the network of this patient population
- Further develop training programmes that meet the needs of practitioners' and patients' networks to optimize their collaboration
- Pay attention to factors that positively influence the job satisfaction of professionals, such as appropriate caseload, clear work tasks, and good training and peer supervision opportunities
- Ensure an available clear regional overview of the possibilities of support in the social domain and how this support can be obtained

**What researchers can do**
- Focus on the perspective of persons in patients' networks regarding their role, needs, and expectations in the support and care of patients with both MID and MH problems

## Combining knowledge and experience

### Integrating multiple sources of knowledge

Providing medical-generalist care, including MH care, is a core value for GPs. GPs and their MHNPs need to have sufficient knowledge and skills to provide this care in a person-centred way.[1] For this, practitioners integrate multiple sources of knowledge: evidence-based knowledge from textbooks, guidelines, and scientific literature; experience-based knowledge grounded on expert opinion; information about the patient and the patient's personal situation, values, and preferences; and information about the local setting and its possibilities and limitations.[40, 41] Practitioners in primary care are particularly adept at practicing this form of care. However, they also indicate that there is only limited evidence-based and experience-based knowledge available on patients with both MID and MH problems, resulting in a feeling of being insufficiently equipped to provide the care needed (**Chapters 2 and 6**).[42]

### Evidence-based knowledge

The limited evidence-based knowledge relates to limited scientific research in this field,[43] as well as the limited accessibility of this knowledge even when it is available (**Chapters 2 and 6**).[43] Although the number of publications on scientific studies involving people with both ID and MH problems in primary care has increased over the years, it is still limited and not specifically focused on people with MID (**Chapter 2**). The reasons for this are that (M) IDs are often inadequately included in general research on MH problems as they are a blind spot for researchers, or a low IQ is frequently an exclusion criterion for participation in scientific research.[43] In my opinion, this is unjustified, considering that 6.4% of the Dutch population has an MID and MH problems are highly prevalent in this group (**Chapter 3**).[44, 45] Another reason, which I have also experienced myself as a researcher, is that individuals with MID are difficult to include in studies because the MID is not always known or registered as such (**Chapters 3 and 4**). A uniform registration of MID in primary care should make people, for whom the MID is known, more easily identifiable for researchers.

In addition, there is the problem of the accessibility and usability of existing evidence-based knowledge for GPs. Guidelines, often based on a combination of evidence-based and experience-based knowledge, have been developed for general primary care to people with ID, in the Netherlands as well as abroad.[24, 32] In addition, specific guidelines have been developed for MH care professionals or a broader audience that address MH problems in people with (M)ID[31, 33] or MID and MH screening tools.[10, 11, 46] Yet, these are often not sufficiently known and used by practitioners in primary care (**Chapters 2 and 6**), as they are not available via the most commonly used practitioner knowledge and quality structures.[5] In the Netherlands, the NHG guideline website is the most common GP knowledge and quality structure and guidance for the care provided by GPs.[47] On this website, only one specific guideline regarding people with ID is available and focuses on physical problems, particularly in individuals with more severe forms of ID. Other NHG guidelines, regarding both somatic and MH issues, lack supplementary information regarding the specific characteristics and needs of individuals with (M)ID.[5]

Although lacking scientific proof, a common belief persists among MH care professionals specialized in MID that the existing GP MH guidelines for people without ID are generally applicable to those with MID, provided that the patient's characteristics are taken into account.[33, 48] Incorporating ID-specific appendices into GP MH guidelines would assist practitioners in considering these characteristics to provide specific recommendations and considerations for this patient group.

However, from our studies, it appears that practitioners also have a need for a more comprehensive guideline regarding MH problems in patients with MID, as practitioners reported difficulties in the assessment, treatment, and follow-up of MH problems in general (**Chapters 2, 3, 5, and 6**).[49] The existing Dutch MH guideline 'Generic Module MH Disorders and Borderline ID or MID' could be suitable here, provided that it is made easily accessible on the NHG guideline website, presented with a direct connection to the GP MH guidelines.[33] Furthermore, further guidance for recognizing, addressing, and assessing MID in patients would also be of value on the NHG website (see also the opportunity 'Early recognition and acknowledgement of MID in patients').

### Practitioners' personal experiences

As mentioned, practitioners integrate multiple sources of knowledge to provide person-centred care to their patients. Personal experience plays an important role in this integration. [41] When there is limited evidence-based knowledge, as is the case in providing care to patients with both MID and MH problems, practitioners have to rely more on their personal experiences. When this is also limited, it can create insecurity in the practitioner and the provision of insufficient care (**Chapters 2 and 6**). [50]

Gaining experience with patients with MID, with or without MH problems, should commence early in the general medical curriculum. It is known that the use of patient educators early in the medical curriculum has a positive effect throughout students' medical career: it provides more insight into patients' perspectives and how patients experience care, and students can apply their knowledge to simulated patients directly. [51] The early involvement of patients with (M)ID also contributes to students' knowledge about, and confidence in, caring for the patient group that is topic of this thesis. [52] Additionally, it is shown that students who undergo an internship in elderly care acquire knowledge and experience that has a positive effect on care for the elderly in general. [53] Therefore, offering and promoting more opportunities for internships in the ID field will help students gain experience in care for patients with (M)ID. The above examples are also relevant for the GP and the MHNP curriculum and for postgraduate training for practitioners. [5]

However, although practitioners are willing to gain more experience, in practice it is a challenge to engage them in training concerning this topic because of the variety of competing medical issues demanding attention (**Chapters 2 and 6).** [54] When practitioners find that they lack experience, it can be valuable for them to know where this experience can be obtained. This can be a GP or an MHNP in the same practice or in the region, or an ID physician who can be approached easily for consultations. If knowledge is consistently and frequently lacking, the previously mentioned ID-NP, with specific experience and knowledge about this patient group, could be a (regional) solution. However, this needs further research and development (see also, the opportunity: 'Longitudinal and relational continuity of primary care').

**Box 7.5.** Recommendations to improve evidence- and experience-based care for patients with both mild intellectual disabilities and mental health problems

**What practitioners can do**
- Register mild intellectual disability (MID) in the medical file properly, so that patients with MID can be identified by researchers
- Follow postgraduate training programmes on patients with MID, with and without mental health (MH) problems
- Know where additional knowledge and experience can be obtained in their practice and/or region

**What practitioners' and patients' networks can do**
- Ensure that intellectual disability (ID) physicians in practitioners' networks are easily accessible for consultations

**What health policymakers can do**
- Ensure that relevant MH guidelines and tools are available within the existing GP guideline structures
- Develop appendices for existing general practitioner (GP) guidelines regarding MH problems with specific recommendations and considerations for patients with MID
- Support development of a GP guideline on recognition, screening, addressing, diagnosing, acknowledging, and registering (M)ID in their patients
- Include patient educators in the general medical, GP, MH nurse practitioner curriculum and postgraduate training to enhance practitioner experience with this patient group
- Offer and promote opportunities for internships in the field of ID care

**What researchers can do**
- Include patients with (M)ID in scientific research
- Conduct more research on various fronts, including:
  - The challenges experienced by practitioners in accurate MH diagnosis
  - The applicability of existing NHG guidelines for MH problems for patients with MID
  - The added value of ID nurse practitioners as a supplement for the lack of practitioners' knowledge and experience

# Domain-transcending collaborative care

## Collaboration in primary MH care

Collaboration in (mental) healthcare is increasingly emphasized by the Dutch government and has led to the Integral Care Agreement. [55] This agreement aims to provide good, accessible, and affordable care and support for patients. Collaboration between various partners, including GPs, the social domain, and specialized services, is central to this initiative. [55] This agreement aligns with the Dutch GPs' core value of collaborative care provision[1] and the Dutch vison document 'Primary care for patients with MH problems'. [56] In patients with both MID and MH problems, collaboration is of extra importance as they often present with multi-problems in various life domains and multiple care professionals can or should be involved with the patient. Often, the practitioner plays a crucial role in coordinating this collaboration (**Chapter 6**).

### Why, when, and with whom to collaborate?

In the case of patients with both MID and MH problems, practitioners' collaboration partners may include professionals from the social domain, ID care, MH services, and hospital. This can vary over time depending on the patient's needs.

In the general population, there is an observed increase in patients seeking help for MH problems where underlying psychosocial problems are evident. [56] This is not surprising, considering that society is becoming more complex and people are increasingly assumed to be self-reliant. [57] Indeed, this applies all the more to people with MID, who face additional social challenges because they lack adequate coping strategies. [57-59] However, the question arises as to whether these psychosocial problems belong to the practitioner's domain or are better addressed by professionals in the social domain or ID care (**Chapter 6**).

When MH problems arise as a result of, or alongside, psychosocial problems, effective treatment of MH problems can be achieved only if psychosocial issues are addressed simultaneously (**Chapter 6**). This is also my experience as an ID physician. If psychosocial problems receive the right attention and support, practitioners may manage mild MH problems effectively using the existing GP guidelines, with necessary adjustments based on the patient's capabilities. [33, 48] More severe or complex forms of MH problems do not fall within the expertise of practitioners and should therefore be treated in, or in close collaboration with, MH services. [56]

Additionally, an ID physician can provide support to a practitioner when questions arise regarding the contribution of MID in MH problems when the practitioner lacks experience in dealing with patients with MID or wants to utilize the ID physician' professional network. [60]

Practitioners believe that effective collaboration on different levels may reduce MH problems, decrease practitioners' work pressure, and prevent more intensive forms of MH care, in some cases (**Chapters 2 and 6**). In addition, inter-professional collaboration around a specific patient or patient group can lead to a more general exchange of knowledge and increased awareness of the possibilities and limitations of other professionals regarding the care needed, and can be helpful in addressing the challenges in providing care across domains. [61]

### The challenges in effective domain-transcending collaborative care

Domain-transcending collaborative care presents a wide variety of challenges that relate partly to issues commonly encountered in primary MH care, including limited capacity in MH services and fragmentation of service delivery when complex MH problems are involved. [56] But patients with MID present additional challenges. Discussing all challenges is too extensive, so I limit myself to those that emerged particularly in the studies in this thesis as being extra relevant for people with MID (**Chapters 2, 5, and 6**) and provide examples of some best practices to address them.

The first challenge lies in finding the right collaborative partners. Practitioners indicate that their regular professional network falls short when they want to organize additional care and support for patients with MID and MH problems, especially regarding non-medical problems (**Chapter 6**). An up-to-date regional network for patients with (M)ID could be helpful in this matter. A successful example of such a network approach is a so-called 'Wally' in the Dutch Deventer care region. [62] A Wally is a social worker who serves as a designated point of contact for practitioners and is available for all patients. Wally is easily approachable by the practitioner and collaborates with the patient to explore support options for psychosocial problems. Although this person is not specifically focused on people with MID, in practice a Wally does offer possibilities for this patient group.

A second challenge lies in bridging long waiting times after referral to MH care or ID care (**Chapters 5 and 6**). [56] Practitioners indicate that, in some cases, formal referral could be prevented if they had the opportunity to consult a psychiatrist or ID physician at short notice. Additionally, this could provide support during the waiting period transition (**Chapter 6**). General practices in both the Netherlands and Canada have had positive experiences with consultative psychiatry for the general population: a psychiatrist visits a practice every one to four weeks and provides practitioners with advice on diagnosis, treatment, or referral to MH services. [63, 64] In Canada, this has resulted in a 66% reduction in referrals to MH services. [64] To implement this for patients with MID, it is, of course, important that the psychiatrist has knowledge and experience regarding patients with MID. Furthermore, consultative ID physicians in general practices may bring additional benefits, but this requires further elaboration and exploration, as the number of ID physician in the Netherlands is very limited.

A third challenge is the observation that a low IQ can be posed by MH services as an exclusion criterion for general MH services, resulting in patients continuing to consult their GP with severe or complex MH problems (**Chapter 6**). [65] This is a surprising stance, given that an estimated 40% of patients in these services are suspected of having MID. [44] This seems like a good reason to make general MH services available to people with MID, also considering that specialized ID MH services are very limitedly available. Fortunately, there are increasingly more MH services such as GGZ Rivierduinen in Leiden, the Netherlands, which has developed treatment modules for patients with MID. [66]

The fourth challenge is to coordinate all care, both medical and non-medical, effectively. Patients with MID expect the practitioner to oversee and coordinate all care relating to the patient and rely on them when problems persist (**Chapters 2, 5, and 6**). Because it seems that no one else is addressing this, practitioners feel responsible for it, but this also consumes a large amount of their time and effort (**Chapter 6**). To support practitioners and to facilitate effective domain-transcending collaboration, regional agreements and initiatives with sufficient project support are needed. This will ensure coordinated care, including clearly defined roles and responsibilities regarding the patient for all stakeholders (**Chapter 2**). [33, 56] A good Dutch example of this is the ‘Blauwe Zorg in de Wijk’ initiative in the province of Limburg, the Netherlands. [61] As part of this initiative, monthly multidisciplinary meetings take place involving GPs, MHNPs, psychiatrists, behavioural scientists, peer support specialists, and professionals from the social domain. In these meetings, patient cases are discussed directly and coordination is optimized, but in addition networking occurs within the GPs' practice making it easier to leverage one another's knowledge and networks. [61] Moreover, we can learn from best practices related to established collaborative care for other vulnerable patient groups, such as vulnerable elderly. [67] It would be valuable to investigate whether such examples of best practices, with adjustments, are also applicable to patients with both MID and MH problems, and how to incorporate the expertise of ID-care professionals, such as the ID physician, into these models. Moreover, it is crucial to establish structured financing agreements for initiatives that involve domain-transcending collaboration, as this element is currently lacking. [56]

**Box 7.6.** Recommendations to strengthen a collaborative and domain-transcending approach in the care for patients with both mild intellectual disabilities and mental health problems

**What practitioners can do**
- Have access to an up-to-date regional network for patients with mild intellectual disability (MID), including the social domain, mental health (MH) services, and intellectual disability care
- Learn from best practices in other practices or regions
- Connect with key professionals in the region and explore whether collaboration agreements are possible
- Ensure adequate information transfer between collaborative partners, including roles and responsibilities regarding the patient

**What practitioners' and patients' networks can do**
- Be easily accessible for practitioners, for both ad-hoc and structural consultations
- Support and contribute to regional collaboration agreements
- Ensure that, in providing care, consideration is given to co-existing MID
- Ensure adequate information transfer between collaborative partners

**What policymakers can do**
- Ensure that (MH) services become inclusive of people with MID and adapt healthcare offerings accordingly
- Give care professionals space to think innovatively, embrace flexibility, and focus on the patient over organizational or financial constraints
- Care organizations and health insurance companies: invest in effective domain-transcending collaboration models and ensure reimbursement

**What researchers can do**
- Focus on the characteristics and added value of (existing) effective domain-transcending collaboration models at patient, professional, and organizational level

## Methodological considerations

This thesis aimed to fill a knowledge gap regarding (primary) MH care for patients with MID. Therefore, the strength of this thesis is that, using evidence-based methodological methods throughout all the studies, we provide insight into quantitative and qualitative characteristics of this care and patient group. The studies in this thesis have various additional strengths. Firstly, by using and linking large datasets, we were able to identify and include people with MID in our quantitative studies (**Chapters 3 and 4**) who were not recorded as such in their medical file and would otherwise have been overlooked.

Secondly, the perspectives of both patients with MID and practitioners have been thoroughly incorporated throughout the entire thesis in three ways. A) An advisory board, consisting of two people with MID, two practitioners, and seven professionals from related fields, was involved in all studies. This board provided feedback on the research design, reflected on the research results, and gave advice on the dissemination of the results. B) A co-researcher with MID was involved in creating the interview guide for the study in **Chapter 5**. The questions were simplified and adjusted to people with MID to optimize the quality of data collection. C) In total, 11 patients and 28 practitioners participated in the qualitative studies in **Chapters 5 and 6** to gain insights into the perspectives of patients receiving care and the practitioners providing the care.

Thirdly, although the supervisory team had broad expertise in the field of primary care, ID care, and (qualitative) research, additional expertise was incorporated into the team as deemed necessary: an epidemiologist and a psychiatrist were added to the team for the study in **Chapter 4** and a GP senior researcher in the studies in **Chapters 5 and 6**. This enhanced the quality of data collection and the interpretation of the results in the respective studies. Finally, the combination of me as an ID physician with affinity and experience with the thesis topic and with the research that I conducted, as well as the practical experience with the patients and the practitioners around whom this thesis revolved, added to the depth of all phases of the studies. The supervisory team and the advisory board were attentive to the possibility that my personal experiences and related convictions might influence interpretation of the results.

This thesis also has limitations. The main limitation lies in identifying people with MID who can be included in studies. Firstly, in the quantitative studies, we were able to include individuals with MID who were not officially registered as such. However, the databases that we used for this purpose did not provide sufficiently precise information about cognitive and adaptive functioning. As a result, with MID as topic, we cannot completely rule out the possibility that individuals with more severe forms of ID or borderline intelligence may also be included in these studies. However, the data linkage approach applied in these studies to identify research participants is unique and currently the best available method to identify individuals with MID in big data in the Dutch setting. Secondly, in the qualitative study in **Chapter 5**, most participants were recruited through their practitioner; people whose MID was a blind spot or were not communicative or were mentally unable to participate were not invited to participate in this study. Moreover, detailed information regarding participants' cognitive and adaptive functioning was not accessible for this study. Although I cannot rule out the possibility that the methods used to identify individuals with MID may have overlooked some perspectives, I am confident that the findings and recommendations in this thesis apply to the majority of people with both MID and MH problems, and therefore have important added value. An additional limitation of this thesis lies in the possibility that the results presented in **Chapters 3–6** are to some extent a product of the Dutch primary care model, thereby limiting external validity. Nevertheless, as several countries have comparable primary care models, the opportunities presented upstream to improve primary MH care and support remain pertinent and can be extended beyond the confines of the Netherlands. Moreover, in nations with less robust formal primary care systems, professionals engaged in non-institutionalized settings, working with individuals experiencing both MID and MH issues, are still likely to encounter many of the challenges outlined in these studies and may benefit from the results and recommendations.

# Conclusion

In conclusion, I can say that patients with both MID and MH problems are a group of patients that frequently turn to their practitioner for care and support. These patients have characteristics that make them vulnerable in primary care and impact the course of their MH trajectory and their lives. I shed light on five opportunities to improve primary MH care and support to this patient group at an early stage in their MH trajectories, upstream, which may affect their lives positively. To effectively implement these opportunities in practice, actions are needed not only from GPs and MHNPs, but also from other care professionals, policymakers, and researchers, preferably in close collaboration with one another, patients, and the network.

### Back to Bob

Suppose the five opportunities proposed in this chapter had been elaborated and applied early in Bob's life, upstream. Would his life story then have unfolded differently, more positively? I cannot provide certainty on that because there are too many individually determined factors and circumstances at play. Would it have given him more chances for a good life? I dare to say yes. What I wish for Bob, for the other 1.17 million people with MID in the Netherlands, and for many more worldwide, is a society and healthcare landscape that is inclusive of individuals with MID, where they receive the (MH) care and support that they need. I hope that, with this thesis, I have contributed to this.

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# Chapter 8

## Summary

## Samenvatting

## Makkelijk lezen samenvatting

# Summary

This thesis focuses on primary mental health (MH) care for people with mild intellectual disabilities (MID). **Chapter 1** provides a general introduction with background information on people with MID, the risks that they face regarding MH problems, the organization of MH care in the Netherlands, and concerns about the current quality of MH care for people with MID.

People with MID are characterized by significant limitations in both intellectual functioning and adaptive skills, with onset during childhood. In the Netherlands, MID is defined with an IQ range from 50 to 85, with such additional limitations in adaptive skills that support is needed to function adequately in daily life. Approximately 6.4% of the Dutch population have MID.

Because of their cognitive and adaptive limitations, people with MID may experience challenges in multiple domains of life, such as housing, employment, and social participation. In addition, the MID may not be directly visible to outsiders, leading to overburden and stress in persons with MID and the provision of inadequate care and support. Up to a third of adults with MID experience MH problems. This is double the general population estimate.

In the Netherlands, just like in most other countries with a primary care model, the general practitioner (GP) is the first point of contact for people with MID that experience MH problems. The GP provides primary MH care and is a gatekeeper to specialist care. The Dutch GP is supported mostly by a mental health nurse practitioner (MHNP) in this regard.

There are several reasons for concern regarding the quality of (primary) MH care for people with MID: GPs do not always feel equipped to provide the care needed; both MID and MH problems may be missed in primary care; and, furthermore, in MH services the quality of care is not assured. Inadequate MH care for people with both MID and MH problems means that such people are at risk of developing more severe or chronic MH problems. Therefore, there is an urgency to find opportunities to improve the quality of MH care for this patient group early in healthcare chain.

This thesis aims to provide insight into the quantitative and qualitative characteristics of MH care for people with MID, with a main focus on the Dutch primary care setting. The findings may provide guidance to improve

MH care for people with MID, which is the overall aim of this thesis. Five main research questions relating to these aims were formulated:

1. What has been described about the care for adult patients with both ID and MH problems provided by the GP?
2. What is the prevalence of MH problems in people with MID and the care provided in primary care, compared with that found for people without ID?
3. What is the prevalence of MH disorders in people with MID and care provided in advanced MH services, compared with that found for people without ID?
4. What are patients' experiences, needs, and suggestions for improvement regarding MH care provided in primary care?
5. What are GPs' and MHNPs' experiences, needs, and suggestions for improvement regarding MH care provided in primary care?

To gain insight into what is known nationally and internationally about primary MH care for people with ID, including potential challenges and opportunities for improvement, a scoping review of the literature was conducted in **Chapter 2**. This review analysed 100 relevant publications from scientific and grey literature, revealing five main themes:

1. **GP role.** GPs play a crucial role in primary MH care and are expected to engage in prevention, diagnosis, treatment, and follow-up. However, the included publications indicate that the current primary MH care is often of an insufficient standard, reflected in underdiagnosis of MH problems, overmedication, and insufficient follow-up.
2. **Knowledge and experience.** The literature demonstrates consensus regarding GPs' limited knowledge and experience in providing care to patients with both MID and MH problems. This is attributed to insufficient training programmes and limited research in this field.
3. **Caregivers' role.** Both formal and informal caregivers are pivotal in recognizing MH problems, seeking help from GPs, facilitating patient–GP information transfer, and executing

treatment plans. GPs' proactive involvement of key persons in the patient's network during the MH care trajectory is emphasized.

4. **Collaboration**. Effective collaboration between GPs and other care professionals is deemed crucial for comprehensive care. The literature describes various aspects of care in which collaboration with diverse professionals can be valuable. At the same time, various preconditions for successful collaboration are outlined, such as accessible referral options, clear referral procedures, adequate information exchange and reimbursement, and consensus on responsibilities.
5. **A standardized approach**. A standardized multidimensional approach, encompassing screening, assessment, and tailored treatment guidelines for patients with ID and MH problems, is deemed beneficial in several publications. Existing guidelines often lack specifications for patients with ID, and GPs may be insufficiently familiar with existing ID-specific tools and guidelines.

The review identified a crucial role for the GP in MH care for these patients, but, with gaps regarding effective training programmes, applicable guidelines and tools, optimal collaborative MH care, and corresponding payment models. Opportunities for improvement lie in prioritizing and investing in bridging these gaps, involving care professionals, scientists, and policymakers.

More knowledge is needed about the care demand and the care provided in primary care for people with both MID and MH problems. By comparing these aspects with the general population, missing insights are obtained to improve primary MH care for people with MID. Therefore, in **Chapter 3**, a retrospective database study was conducted with the aim of providing an overview of the prevalence of MH problems in people with MID in primary care, and the care provided in terms of consultations and type of medication prescriptions, compared with people without ID. In this database study, a primary care database from the Netherlands Institute for Health Services Research (Nivel) was linked to the MID database from Statistic Netherlands (SN), thereby identifying 11,887 people with MID.

Of the people with MID, almost half experienced MH problems during the four-year research period, compared with 30% of people without ID. They were younger and had a higher number of unique problems. Particular International Classification of Primary Care (ICPC) codes associated with substance abuse, psychosis, and unspecified diagnosis were more prevalent in people with MID. GPs provided significantly more consultations and types of medication prescriptions to people with both MID and MH problems compared with people of the same age and gender without ID or with MID alone. Particular antipsychotics were frequently prescribed to people with MID. In 80% of the identified patients with MID, the GP had not used the ICPC code P85 (mental retardation) to register the ID in the medical file, suggesting that the MID may not have been known to the GP.

The findings indicate that more people with MID consult their GP with MH problems, compared with those without ID. Additionally, this patient group has higher healthcare needs than people without ID or with MID alone, leading to a corresponding increase in workload for the GP. Moreover, the results suggest that GPs struggle to register the MID as such, to establish the correct MH diagnosis, and, consequently, to provide appropriate treatment.

In the case of severe or complex MH problems in people with MID, GPs often collaborate with MH services. Therefore, there is also a need for more information on the prevalence of MH disorders and the MH care provided to patients with MID in MH services, compared with patients without ID. In **Chapter 4**, a population-based retrospective database study was conducted over a three-year period, where an SN-MH service database was linked with the SN-MID database to identify 7,596 patients with MID.

Similar to primary care, we observed an under-registration of MID in patients' files in MH services. For 61% of the patients with MID, there was no record of an ID status in the MH service database. Compared with the patients without ID, patients with MID were diagnosed with different MH disorders. Particularly in the patient group with MID where the ID was not registered in the patient's file, more patients had a 'No or an unknown diagnosis' compared with patients without ID. Patients with MID were younger, were provided with shorter MH trajectories, and were more likely to receive care in an addiction or forensic setting. In addition, MH service professionals

performed fewer diagnostic and treatment activities in patients with MID compared with patients without ID, while conducting significantly more indirect patient care activities, such as interprofessional consultations. At the same time, crisis interventions and MH hospital admissions were more frequent in patients with MID.
The findings of this study show indications that MIDs are insufficiently taken into account in MH trajectories and that patients with MID may be undertreated in MH services. This may contribute to the high number of crisis interventions and MH hospital admissions found in this patient group.

Through qualitative research, the above quantitative findings were further elucidated with perspectives from patients, GPs, and MHNPs. **Chapter 5** describes the patients' perspectives regarding their received primary MH care. Eleven semi-structured interviews were conducted with participants who had visited their practitioner[1] for MH problems in the previous 12 months, using the Person-Centred Primary Care Measures, a patient-reported instrument, as a guide. Thematic analysis revealed four themes:

1. **Cumulative vulnerability.** Participants experienced vulnerability arising from their MID, intensified by MH problems. In relation to this vulnerability, they mentioned challenges in recognizing MH problems in oneself, uncertainty about practitioners' accessibility for MH problems, communication issues with the practitioner, and carrying out practitioner advice. Vulnerability is accompanied by various additional patient needs, further described in the following themes.
2. **Patient needs regarding the GP.** Participants considered it important for practitioners to acknowledge MID without reminders. Easy access to the practitioner for MH problems was crucial, with expectations of the practitioner reacting promptly and assuming a supportive and coordinating role. A strong doctor–patient relationship was essential, and some participants favoured MHNPs for their time, informality, and reduced tendency to dismiss somatic problems as psychological.

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[1] For the sake of readability, practitioner is stated where it applies to both GPs and MHNPs. When necessary, GP or MHNP is specified.

3. **Patient needs regarding the network**. Participants valued their network's opinion and support regarding MH problems. They rely on them for emotional support, identification and assessment of MH problems, and encouragement to contact the practitioner when needed. Presence during practitioner consultations and assistance in implementing practitioner advice were seen as supportive.
4. **Self-determination.** Participants emphasized the need for self-determination with regard to their MH trajectory, despite their vulnerabilities and additional needs for support.

The patients' perspective highlights heightened vulnerability in accessing primary care for individuals with both MID and MH problems. As a result, patients have additional needs and expectations regarding the practitioner and the network, emphasizing the pivotal role of self-determination.

**Chapter 6** describes GPs' and MHNPs' perspectives regarding the MH care that they provide to people with MID. Four focus groups, with 19 GPs and 9 MHNPs, were conducted, using the four themes that emerged from the patient interview study described in Chapter 5 as input.
Thematic analysis revealed four themes:

1. **Practitioners' struggles with adapting to challenging patient characteristics.** Participants indicated that these patients often present with multiple problems, lack clear reasons for encounter, and struggle with organizing their own care. They also mentioned that they do not always recognize the MID in patients or know how to address their suspicion of it. Enhancing MH care involves improving practitioners' knowledge and experience, practitioners addressing patients' additional needs, and practitioners adapting approaches beyond standard MH guidelines.
2. **Importance and difficulties of establishing a good doctor–patient relationship.** Participants considered it crucial to invest in a sustainable doctor–patient relationship for this patient group. However, establishing this relationship may be challenging given the vast experiential differences and patients' potentially negative past encounters with healthcare providers.

3. **Facilitating and hampering roles of patients' networks**. Patients may have supportive networks, aiding practitioners with valuable insights and contributing to patient stability. However, networks can also be part of patients' problems, impacting MH negatively. Participants consider that cooperation with the network is valuable but demands additional time and effort.
4. **GPs' and MHNPs' challenges in providing care in the healthcare chain**. According to the participants, timely access to appropriate care and support can reduce MH problems. However, participants experience challenges as a result of insufficient professional networks, poorly accessible MH services, and unclear reimbursement. In addition, there is a lack of coordination between involved professionals, with practitioners frequently assuming this role, leading to new challenges and frustrations.

The GPs' and MHNPs' perspectives reveal that they perceive patients with both MID and MH problems as complex. To provide effective MH care, they find it important to consider MID throughout the trajectory, invest in the doctor–patient relationships, and establish a stable and sustainable network and coordinated collaborative care around the patient.

The suggestions for improvement mentioned by patients, GPs, and MHNPs are integrated with the main findings of the studies in Chapters 2 to 6 in **Chapter 7**, providing a general discussion. The findings of these studies show that patients with both MID and MH problems have particular characteristics that impact the course of their MH trajectory and their lives. This includes encountering MH problems at a young age, experiencing multi-problems, needing a supportive network, being potentially undertreated in MH services, and their MID being overlooked by care professionals. GPs play a crucial role in the MH care of patients with MID, facing challenges in providing and coordinating appropriate care and support to this patient group.

In this chapter, I highlight and elaborate five opportunities to improve primary (MH) care and support for this patient group. For all opportunities, I provide recommendations at GP, network, policy, and research level.

- **Early recognition and acknowledgement of MID in patients.** Recognizing and acknowledging MID is essential for person-centred care. Practitioners experience problems in MID recognition because of insufficient knowledge and experience, limited screening tools, and discomfort discussing potential MID with patients. In addition, accessibility and full reimbursement of IQ tests are crucial. Once MID is established, it is vital to register the information in the patient's medical file. Practitioners' responsibility for early recognition extends to other care professionals in both the practitioners' and the patients' networks.
- **Continuity of care**. Continuity of care is expected to have a positive effect on both the primary MH trajectory and the MH outcome for patients with MID. However, achieving continuity is under pressure from current societal developments, with implications for practitioners, GP practices, and healthcare organizations. Task substitution may improve continuity of care, for instance, by integrating an ID nurse practitioner (ID-NP), whose job profile should be further developed.
- **The supportive role of patients' (in)formal networks.** Persons in the patient's network can be supportive for both the practitioner and the patient with MID and MH problems. It is therefore important to strengthen the network by addressing potential gaps in knowledge, experience, and skills, or to refer them to social services for additional support when needed. Ensuring continuity in the patient's network is vital to enhance collaboration and information exchange with the practitioner.
- **Combine knowledge and experience.** Integrating multiple sources of knowledge is crucial for GPs in providing MH care to patients with MID. However, there is limited evidence-based knowledge available regarding this patient group, given the limited scientific research in this field as well as the limited accessibility of the available knowledge. Consequently, GPs have to rely more on their personal experience-based knowledge, emphasizing the need for GPs' early and frequent exposure to patients with MID in their medical training. When

GPs lack personal experience, it is useful for them to know who possesses this experience-based knowledge, such as a GP with a special interest in this patient group or an ID physician.

- **Domain-transcending collaborative care.** In patients with both MID and MH problems, collaboration is of extra importance, as they often present with multi-problems and multiple care professionals from the social domain, MH care, and ID care may be involved. Challenges for effective collaborative care include finding the right collaborative partners, long waiting times after referral to MH or ID care, a low IQ as an exclusion criterion for general MH services, and overseeing and coordinating all care. However, there are already best practices at regional level, in adjacent sectors, and internationally regarding collaborative care from which we can learn.

In conclusion, patients with both MID and MH problems form a vulnerable group that often relies on GPs. The elaboration and implementation of the five identified opportunities to improve primary (MH) care and support for this patient group require coordinated and collaborative efforts from GPs, other care professionals, policymakers, and researchers.

# Samenvatting

Dit proefschrift richt zich op de psychische zorg aan mensen met een lichte verstandelijke beperking (LVB) in de huisartspraktijk. In **Hoofdstuk 1** wordt in een algemene inleiding meer achtergrondinformatie gegeven over mensen met een LVB, de risico's die zij lopen op psychische problemen, de organisatie van psychische zorg in Nederland, en de zorgen die er bestaan over de huidige kwaliteit van deze zorg aan mensen met een LVB.

Mensen met een LVB worden gekenmerkt door beperkingen zowel in het intellectuele functioneren als in adaptieve vaardigheden, met een aanvang in de kinderleeftijd. In Nederland spreekt men van een LVB indien er sprake is van een IQ tussen de 50 tot 85, met dusdanige beperkingen in adaptieve vaardigheden dat ondersteuning nodig is om adequaat te functioneren in het dagelijks leven. Ongeveer 6,4% van de Nederlandse bevolking heeft een LVB.

Vanwege de cognitieve en adaptieve beperkingen kunnen mensen met een LVB uitdagingen ervaren op meerdere levensdomeinen, zoals wonen, werken en sociale participatie. De LVB is mogelijk niet direct zichtbaar voor buitenstaanders, wat kan leiden tot overbelasting en stress bij personen met een LVB en tot onthouding van passende zorg en ondersteuning. Tot één derde van volwassenen met een LVB ervaart psychische problemen, wat twee keer zo hoog is als de algemene bevolking.

In Nederland, net als in de meeste andere landen met een eerste-lijnszorgmodel, is de huisarts het eerste aanspreekpunt voor mensen met een LVB die psychische klachten ervaren. De huisarts biedt eerstelijns psychische zorg en fungeert als poortwachter naar meer specialistische zorg. De Nederlandse huisarts wordt hierbij ondersteund door de praktijkondersteuner GGZ (POH-GGZ).

Er zijn echter verschillende redenen tot zorg met betrekking tot de kwaliteit van de (eerstelijns) psychische zorg aan mensen met een LVB: huisartsen voelen zich niet altijd voldoende toegerust om de benodigde zorg te bieden; zowel een LVB als de psychische problemen kunnen over het hoofd worden gezien; en ook in geestelijke gezondheidszorg (GGZ) is de kwaliteit van zorg niet gegarandeerd. Door ontoereikende psychische zorg lopen mensen met een LVB het risico op het ontwikkelen van ernstigere of chronische psychische problemen. Daarom is er een urgentie om de kwaliteit van deze zorg bij voorkeur vroeg in de zorgketen te verbeteren.

Dit proefschrift beoogt inzicht te geven in kwantitatieve en kwalitatieve karakteristieken van de psychische zorg aan mensen met LVB, met de nadruk op de Nederlandse huisartsenzorg. Deze informatie geeft richting aan verbeteringen van deze zorg voor deze patiëntengroep, wat het overkoepelende doel van dit proefschrift is.
De volgende vijf onderzoeksvragen zijn geformuleerd:

1. Wat is er beschreven over de zorg die huisartsen verlenen aan volwassen patiënten met zowel een verstandelijke beperking (VB) als psychische problemen?
2. Wat is de prevalentie van psychische problemen bij mensen met een LVB bij de huisarts en welke zorg wordt er vervolgens verleend? Zijn er verschillen met mensen zonder een VB?
3. Wat is de prevalentie van psychische problemen bij mensen met een LVB in de gespecialiseerde GGZ en welke zorg wordt er vervolgens verleend? Zijn er verschillen met mensen zonder een VB?
4. Wat zijn de ervaringen, behoeften en suggesties van patiënten met zowel een LVB als psychische problemen met betrekking tot de psychische zorg die ze hebben ontvangen bij de huisarts?
5. Wat zijn de ervaringen, behoeften en suggesties van huisartsen en POH's-GGZ met betrekking tot de psychische zorg die ze geven aan patiënten met een LVB?

Om inzicht te krijgen in wat er nationaal en internationaal bekend is over de psychische zorg aan mensen met een VB, inclusief mogelijke knelpunten en verbeteropties, is in **Hoofdstuk 2** een scoping review van de literatuur uitgevoerd. Dit literatuuronderzoek omvatte honderd relevante publicaties uit zowel wetenschappelijke als grijze literatuur, waarbij een thematische analyse vijf overkoepelende thema's onthulde.

1. **Rol van de huisarts.** Huisartsen hebben een belangrijke rol in de psychische zorg voor mensen met een VB en zijn betrokken bij preventie, diagnose, behandeling en follow-up van psychische problemen. Uit de geïncludeerde studies blijkt echter dat

de kwaliteit van huidige psychische huisartsenzorg vaak onvoldoende is, wat zich uit in onderdiagnose van psychische problemen, over-medicatie en gebrekkige follow-up.

2. **Kennis en ervaring.** De literatuur toont consensus over beperkte kennis en ervaring onder huisartsen in de zorg voor patiënten met zowel een VB als psychische problemen, mede door onvoldoende onderwijsprogramma's en wetenschappelijk onderzoek op dit gebied.
3. **Rol van verzorgers.** Zowel formele als informele verzorgers spelen een essentiële rol bij de herkenning van psychische problemen, de zoektocht naar hulp, ondersteuning bij informatieoverdracht en uitvoering van behandelplannen. Voor adequate zorg is het daarom belangrijk dat de huisarts proactief sleutelpersonen uit het netwerk van de patiënt betrekt.
4. **Samenwerking.** Effectieve samenwerking tussen huisartsen en andere zorgprofessionals is cruciaal. De literatuur beschrijft verschillende aspecten van zorg waarin samenwerking met diverse professionals waardevol kan zijn. Tegelijkertijd worden er verschillende voorwaarden aan goede samenwerking geschetst zoals toegankelijke doorverwijsopties, duidelijke verwijsprocedures, goede informatie-uitwisseling, passende financiering en consensus over verantwoordelijkheden.
5. **Een gestandaardiseerde aanpak.** Een gestandaardiseerde aanpak ten aanzien van screening, beoordeling en behandeling van patiënten met een VB en psychische problemen wordt in verscheidene publicaties als helpend gezien. Bestaande richtlijnen missen vaak specificaties voor patiënten met een VB, en huisartsen zijn onvoldoende bekend met bestaande VB-specifieke instrumenten en richtlijnen.

Dit literatuuronderzoek identificeerde een cruciale rol voor de huisarts in psychische zorg voor deze patiënten, maar schetst ook de hiaten met betrekking tot effectieve onderwijsprogramma's voor huisartsen, toepasbare richtlijnen en tools, optimale samenwerking met de GGZ, en daarbij passende financiering. Investeren in de overbrugging van deze hiaten, met de betrokkenheid van zorgprofessionals, beleidsmakers en wetenschappers, zou de zorg kunnen verbeteren.

Er is meer kennis nodig over de zorgvraag van patiënten met zowel een LVB als psychische problemen en de zorg die hen geboden wordt in de huisartsenpraktijk. Door deze aspecten te vergelijken met de algemene bevolking, worden ontbrekende inzichten verkregen om de zorg bij de huisarts goed vorm te geven. Daarom is er in **Hoofdstuk 3** een retrospectieve databasestudie uitgevoerd met als doel overzicht te geven van de prevalentie van psychische problemen bij mensen met een LVB in de Nederlandse huisartsenpraktijk, en de geleverde zorg in termen van consultaties en het type voorgeschreven medicatie. Dit is vergeleken met mensen zonder een VB. In deze datastudie werd een landelijke representatieve eerstelijnszorgdatabase van het Nederlands Instituut voor Onderzoek van de Gezondheidszorg (Nivel) gekoppeld met de LVB-dataset van het Centraal Bureau voor de Statistiek (CBS) om 11.887 mensen met een LVB te identificeren.

Bijna de helft (49%) van de mensen met een LVB ervoer gedurende de vierjarige onderzoeksperiode psychische problemen, vergeleken met 30% van de mensen zonder een VB. De LVB-groep was jonger en had meer unieke psychische problemen. Specifieke ICPC (International Classification of Primary Care) codes geassocieerd met middelenmisbruik, psychose en ongespecificeerde diagnose kwamen vaker voor bij mensen met een LVB. Huisartsen hadden significant meer consulten en schreven meer verschillende soorten medicamenten voor aan patiënten met zowel een LVB als psychische problemen in vergelijking met patiënten met dezelfde leeftijd en geslacht zonder VB of met alleen een LVB. Met name antipsychotica werden vaak voorgeschreven aan patiënten met een LVB. In 80% bleek de ICPC code P85 (mentale retardatie) niet gebruikt om de VB in het medisch dossier te registreren en is de VB mogelijk niet bekend bij de huisarts.

De bevindingen geven aan dat meer mensen met een LVB met psychische problemen bij de huisarts komen dan mensen zonder VB. En dat deze patiëntgroep bovendien een hogere zorgbehoefte heeft dan mensen zonder VB of alleen een LVB, hetgeen een overeenkomstige hogere werkdruk geeft bij de huisarts. Bovendien geven de resultaten een indicatie dat huisartsen moeite hebben om de LVB als zodanig te registreren, de juiste psychische diagnose vast te stellen en bijgevolg passende behandeling te bieden.

Bij ernstige of complexe psychische problemen bij mensen met een LVB werkt de huisarts veelal samen met zorgverleners uit de gespecialiseerde GGZ. Daarom is er ook meer kennis nodig over de prevalentie van psychische aandoeningen en de zorg die wordt geboden aan patiënten met een LVB in de gespecialiseerde GGZ, in vergelijking met patiënten zonder VB. In **Hoofdstuk 4** werd daarom een retrospectieve databasestudie uitgevoerd over een periode van drie jaar, waarbij populatiedata van het CBS met betrekking tot de gespecialiseerde GGZ werden gekoppeld aan de LVB-dataset van het CBS, om 7.596 patiënten met een LVB te identificeren.

Net als in de huisartspraktijken zien we hier een onderregistratie van de VB in de patiëntendossiers; in 61% van de patiënten met een LVB was er geen registratie van een VB in de database van de gespecialiseerde GGZ. In vergelijking met patiënten zonder VB werden bij patiënten met een LVB andere typen psychische aandoeningen vastgesteld. Met name de LVB-groep waarbij de VB niet in het patiëntendossier geregistreerd stond, had een groter aantal patiënten een ‘Geen’ of ‘Onbekende’ diagnose in vergelijking met patiënten zonder VB. Daarnaast waren patiënten met een LVB jonger, kregen ze kortere trajecten aangeboden en kregen ze vaker zorg in een verslavings- of forensische setting. Bovendien voerden professionals in de GGZ minder diagnostische en behandelingsactiviteiten uit bij patiënten met een LVB in vergelijking met patiënten zonder VB, terwijl ze aanzienlijk meer indirecte patiëntenzorgactiviteiten uitvoerden, zoals consultaties van professionals buiten de GGZ. Tegelijkertijd kwamen crisisinterventies en opnames in de geestelijke gezondheidszorg vaker voor bij patiënten met een LVB.

De bevindingen van deze studie geven een indicatie dat er in de gespecialiseerde GGZ onvoldoende rekening wordt gehouden met een LVB, en dat patiënten met een LVB hier mogelijk worden onderbehandeld. Dit kan bijdragen aan het hoge aantal crisisinterventies en opnames in de GGZ die we hebben gevonden bij deze patiëntengroep.

Door middel van kwalitatief onderzoek zijn bovenstaande kwantitatieve bevindingen verder geduid met perspectieven van patiënten, huisartsen en POH’s-GGZ. **Hoofdstuk 5** beschrijft de ervaringen en behoeften van patiënten met een LVB met betrekking tot ontvangen psychische zorg van de huisarts en de POH-GGZ. Elf semigestructureerde interviews werden gehouden met deelnemers die in de afgelopen 12 maanden hun huisarts[2] hadden bezocht voor psychische problemen, waarbij de Person-Centred Primary Care Measures, een patiënten-rapportage instrument over aspecten van de huisartsenzorg, als leidraad voor het interview dienden. Thematische analyse onthulde vier thema's:

1. **Cumulatieve kwetsbaarheid.** Deelnemers ervaarden kwetsbaarheid als gevolg van hun LVB, versterkt door psychische problemen. Gerelateerd aan deze kwetsbaarheid noemden zij uitdagingen in het herkennen van psychische problemen bij zichzelf, onzekerheid over de toegankelijkheid van de huisarts voor psychische problemen, communicatieproblemen met de huisarts en het uitvoeren van diens adviezen. De kwetsbaarheid gaat gepaard met diverse extra patiëntbehoeften, in de volgende thema's verder beschreven.
2. **Patiëntbehoeften met betrekking tot de huisarts.** Deelnemers vonden het belangrijk dat de huisarts rekening houdt met hun LVB zonder dat ze dit steeds moeten aangeven. Eenvoudige toegang tot de huisarts bij psychische problemen is cruciaal, en patiënten verwachten een snelle reactie, alsmede een ondersteunende en coördinerende rol van de huisarts. Een goede arts-patiëntrelatie is essentieel, maar sommige deelnemers gaven de voorkeur aan de POH-GGZ vanwege meer tijd, informele benadering en verminderde neiging om somatische problemen als psychische af te doen.
3. **Patiëntbehoeften met betrekking tot hun netwerk**. Deelnemers waardeerden de mening en steun van hun netwerk met betrekking tot psychische problemen. Ze vertrouwden erop voor emotionele ondersteuning, het herkennen en beoordelen van psychische problemen, en het aanmoedigen om contact op te nemen met de huisarts wanneer dat nodig was. Aanwezigheid tijdens huisartsconsult en hulp bij het opvolgen van het advies van de huisarts ervaarden zij als helpend.
4. **Eigen regie**. Deelnemers benadrukten de behoefte aan eigen regie, ondanks hun kwetsbaarheid en extra ondersteuningsbehoeften met betrekking tot hun huisarts en netwerk.

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[2] Voor de leesbaarheid wordt de term huisarts gebruikt waar het van toepassing is op zowel de huisarts als de POH-GGZ. Indien van toepassing wordt specifiek vermeld wanneer het de huisarts of POH-GGZ betreft.

Het perspectief van de patiënten laat zien dat mensen met een LVB en bijkomende psychische problemen zich extra kwetsbaar voelen bij de huisarts. Hierdoor hebben ze aanvullende behoeften en verwachtingen ten aanzien van hun huisarts, POH-GGZ en hun netwerk, met behoud van eigen regie.

**Hoofdstuk 6** beschrijft de ervaringen, behoeften en suggesties voor verbeteringen van huisartsen en POH's-GGZ met betrekking tot de psychische zorg die zij geven aan mensen met een LVB. Deze werden opgehaald in vier focusgroepen, met 19 huisartsen en 9 POH's-GGZ, waarbij de vier thema's die voortkwamen uit de interviewstudie met patiënten, beschreven in hoofdstuk 5, als leidraad dienden. Thematische analyse onthulde vier thema's:

1. **Uitdagingen voor huisartsen bij deze specifieke patiëntengroep.** Deelnemers geven aan dat deze patiënten zich vaak presenteren met meerdere problemen, geen duidelijke hulpvraag hebben en moeite hebben met het organiseren van hun eigen zorg. Ook geven ze aan dat ze niet altijd de LVB in patiënten herkennen of weten hoe hun vermoeden ervan aan te kaarten. Suggesties om psychische zorg te verbeteren omvatten het vergroten van de kennis en ervaring, het onderkennen van extra zorg en ondersteuningsbehoeften van deze patiënten, en waar nodig het verlenen van zorg buiten de geldende richtlijnen.
2. **Het belang van een goede arts-patiëntrelatie en moeilijkheden bij het realiseren daarvan.** Door deelnemers werd het investeren in een duurzame arts-patiëntrelatie als cruciaal gezien voor deze patiëntengroep. Het opbouwen van deze relatie kan echter uitdagend zijn vanwege grote ervaringsverschillen en mogelijke eerdere negatieve ervaringen van de patiënt met zorgverleners.
3. **De faciliterende en belemmerende rollen van het netwerk van de patiënt.** Patiënten kunnen ondersteunende netwerken hebben die huisartsen voorzien van waardevolle inzichten en bijdragen aan de stabiliteit van de patiënt. Netwerken kunnen echter ook deel uitmaken van het probleem van de patiënt

en zo diens psychische gezondheid negatief beïnvloeden. Samenwerking met het netwerk werd door de deelnemers als waardevol gezien, maar vereist extra tijd en inspanning.

4. **Uitdagingen van huisartsen bij het bieden van zorg in de zorgketen.** Volgens de deelnemers kan tijdige toegang tot passende zorg en ondersteuning psychische problemen verminderen. Deelnemers ervaren uitdagingen als gevolg van een ontoereikend professioneel netwerk, slecht toegankelijke GGZ en onduidelijkheid over financiering van zorg. Daarnaast ontbreekt afstemming tussen betrokken professionals, waarbij huisartsen vaak deze rol op zich nemen, wat leidt tot nieuwe uitdagingen en frustraties.

De perspectieven van huisartsen en POH's-GGZ tonen aan dat zij patiënten met een LVB in combinatie met psychische problemen als complex beschouwen. Om effectieve psychische zorg te bieden, vinden zij het belangrijk om rekening te houden met de LVB gedurende het gehele traject, extra te investeren in de arts-patiëntrelatie en een stabiel en duurzaam netwerk van zorgprofessionals en informele ondersteuners tot stand te brengen waarin gecoördineerd wordt samengewerkt rondom de patiënt.

De door de patiënten, huisartsen en POH's-GGZ genoemde suggesties voor verbeteringen zijn geïntegreerd met de belangrijkste bevindingen van de studies uit de hoofdstukken 2 tot en met 6 in **Hoofdstuk 7**, waarin een algemene beschouwing wordt gegeven. De bevindingen tonen aan dat patiënten met zowel een LVB als psychische problemen specifieke kenmerken hebben die van invloed zijn op het verloop van hun zorgtraject en hun leven. Zo ervaren ze vaak al psychische problemen op jonge leeftijd, hebben ze meerdere problemen tegelijkertijd, en is er behoefte aan een ondersteunend netwerk. Daarnaast zien we mogelijke onderbehandeling in de GGZ en zorgprofessionals die de LVB over het hoofd zien. Huisartsen spelen een cruciale rol in de psychische zorg voor deze patiënten maar staan voor uitdagingen bij het bieden en coördineren van passende zorg en ondersteuning.

In dit hoofdstuk bespreek ik vijf opties om de psychische zorg en ondersteuning bij de huisarts aan patiënten met een LVB te verbeteren. Voor alle verbeteropties geef ik aanbevelingen op het niveau van de huisarts, het netwerk, beleid en onderzoek.

- **Vroegtijdige herkenning en erkenning van een LVB bij patiënten.** Het herkennen en erkennen van een LVB is essentieel voor persoonsgerichte zorg. Huisartsen ervaren problemen met de LVB-herkenning vanwege onvoldoende kennis en ervaring, beperkte screeningsinstrumenten en het zich ongemakkelijk voelen bij het bespreken van een mogelijke LVB met patiënten. Daarnaast zijn toegankelijkheid en volledige vergoeding van IQ-tests cruciaal. Na het vaststellen van een LVB is het van vitaal belang om de informatie in het medische dossier van de patiënt te registreren. De verantwoordelijkheid van huisartsen voor vroegtijdige herkenning strekt zich uit naar andere zorgprofessionals in het netwerk van de huisarts en dat van de patiënt.
- **Continuïteit van zorg.** Continuïteit van zorg kan een positief effect hebben op zowel het zorgtraject als de uitkomst voor patiënten met een LVB en psychische problemen. Het bereiken van continuïteit staat echter onder druk door de huidige maatschappelijke ontwikkelingen met gevolgen voor de huisarts, de huisartsenpraktijk, en de organisatie van de gezondheidszorg in Nederland. Taaksubstitutie kan mogelijk de continuïteit verbeteren, bijvoorbeeld door het inzetten van een praktijkondersteuner-VB, wiens functieprofiel nog verder uit ontwikkeld zou moet worden.
- **De ondersteunende rol van het (in)formele netwerk van de patiënt**. Personen in het netwerk van de patiënt kunnen ondersteunend zijn voor zowel de huisarts als de patiënt. Het is daarom belangrijk om het netwerk van de patiënt te betrekken, maar ook te versterken door mogelijke hiaten in kennis, ervaring en vaardigheden aan te pakken, of door te verwijzen naar sociale voorzieningen voor aanvullende ondersteuning wanneer dat nodig is. Het waarborgen van continuïteit binnen het netwerk van de patiënt is essentieel om samenwerking en informatie-uitwisseling met de huisarts te bevorderen.

- **Combineer kennis en ervaring**. Meerdere bronnen van kennis integreren is cruciaal voor huisartsen wanneer zij psychische zorg bieden aan patiënten met een LVB. Er is echter weinig evidence-based kennis beschikbaar over deze patiëntengroep, vanwege beperkt wetenschappelijk onderzoek op dit gebied en de onvoldoende toegankelijkheid van bestaande kennis. Als gevolg daarvan moeten huisartsen meer vertrouwen op hun persoonlijke ervaringskennis, wat benadrukt hoe belangrijk het is dat huisartsen vroeg en frequent in hun medische opleiding in contact komen met patiënten met een LVB. Bij gebrek aan persoonlijke ervaring kan het waardevol zijn om te weten bij wie deze ervaringskennis wel aanwezig is, zoals bij een collega-huisarts met belangstelling voor deze doelgroep of een arts voor mensen met een VB (Arts VG).
- **Domeinoverstijgende samenwerking in de zorg.** Bij patiënten met zowel een LVB als psychische problemen is samenwerking in de zorg(keten) extra belangrijk, omdat ze vaak te maken hebben met meerdere problemen en er meerdere zorgprofessionals betrokken kunnen zijn uit het sociale domein, GGZ en de verstandelijk gehandicapten (VG)-zorg. Uitdagingen voor effectieve samenwerking zijn: de juiste samenwerkingspartners vinden; lange wachttijden na verwijzing naar GGZ of VG-zorg; een laag IQ als uitsluitingscriterium voor de algemene GGZ; en overzicht op en coördinatie van alle zorg. Er zijn echter reeds best practices op regionale schaal, in aanpalende sectoren en internationaal met betrekking tot samenwerkingen waar we van kunnen leren.

Samenvattend vormen patiënten met zowel een LVB als psychische problemen een kwetsbare groep die vaak een beroep doet op de huisarts. De uitwerking en implementatie van de vijf geïdentificeerde opties om psychische zorg in de huisartsenpraktijk te verbeteren, vereist gecoördineerde en gezamenlijke inspanningen van zowel huisartsen, andere zorgprofessionals, beleidsmakers als onderzoekers.

# Makkelijk lezen samenvatting

Door: Katrien Pouls en Anneke van der Cruijsen

## Hoofdstuk 1

### Inleiding

#### Wat staat er in dit boek?
In dit boek staat een onderzoek opgeschreven.
Het onderzoek gaat over mensen met een lichte verstandelijke beperking en psychische problemen.
Bij psychische problemen kun je bijvoorbeeld denken aan je somber voelen, bang zijn, of een depressie.

#### Waarom doen we dit onderzoek?
We weten dat mensen met een lichte verstandelijke beperking vaker psychische problemen hebben dan mensen zonder verstandelijke beperking.
Helaas krijgen deze mensen niet altijd de juiste zorg.

De huisarts is vaak de eerste dokter waar mensen met psychische problemen naartoe gaan.
Het is belangrijk dat ze daar meteen de juiste hulp krijgen.

We wisten nog niet veel over de psychische zorg bij de huisarts aan mensen met een lichte verstandelijke beperking.
Bijvoorbeeld: hoe vaak komen ze bij de huisarts met psychische problemen?
Wat voor zorg geeft de huisarts dan?
Wat gaat er goed?
Wat gaat er minder goed?

Pas als we hier de antwoorden op weten, kunnen we nadenken over hoe we de psychische zorg bij de huisarts kunnen verbeteren.
Daarom doen we dit onderzoek.

## Wat waren de belangrijkste vragen voor het onderzoek?

De vijf belangrijkste vragen voor het onderzoek waren:

1. Wat is er al in artikelen geschreven over psychische zorg aan mensen met een verstandelijke beperking bij de huisarts?
2. Hoeveel van de mensen met een lichte verstandelijke beperking komt bij de huisarts met psychische problemen?
   Wat voor soort psychische problemen zijn dit en welke zorg krijgen ze dan?
3. Met wat voor psychische problemen komen mensen met een lichte verstandelijke beperking in de Geestelijke Gezondheidzorg (GGZ) en welke zorg krijgen ze dan?
4. Hoe denken mensen met een lichte verstandelijke beperking over de psychische zorg die ze hebben gekregen van de huisarts?
5. Hoe denken huisartsen en praktijkondersteuners (POHs) over de psychische zorg die ze geven aan mensen met een lichte verstandelijke beperking?

# Hoofdstuk 2

## Wat is er al in artikelen geschreven over psychische zorg aan mensen met een verstandelijke beperking bij de huisarts?

### Wat wilden we weten?

We wilden weten wat er al is opgeschreven over de psychische zorg aan mensen met een verstandelijke beperking bij de huisarts.

### Wat hebben we gedaan?

We hebben gezocht naar teksten in tijdschriften en op websites.
Die moesten gaan over:

- mensen met een verstandelijke beperking;
- psychische problemen;
- zorg bij de huisarts.

Deze teksten zijn we gaan lezen.

### Wat zijn we te weten gekomen?

Vijf onderwerpen kwamen steeds weer terug in de teksten.
Per onderwerp hebben we opgeschreven wat ons is opgevallen.

### 1. De rol van de huisarts

De huisarts is belangrijk voor het:

- voorkomen;
- herkennen;
- behandelen;
- volgen van psychische problemen.

Dit blijkt niet altijd goed te gaan.

### 2. Kennis en ervaring

Er is weinig onderzoek gedaan naar psychische problemen bij mensen met een verstandelijke beperking.
Huisartsen krijgen weinig onderwijs hierover.
Huisartsen hebben niet veel kennis en ervaring.

### 3. Rol van begeleiders of familie

Begeleiders en familie kunnen helpen om:

- te besluiten om naar de huisarts te gaan;
- informatie te geven aan de huisarts;
- te begrijpen wat de huisarts zegt;
- de behandeling goed te laten verlopen.

### 4. Samenwerking

Het helpt als de huisarts goed samenwerkt met andere zorgverleners, zoals psychiaters of woonbegeleiders.

Bij een goede samenwerking horen ook goede afspraken over wie wat doet.

### 5. Werken volgens vaste afspraken

Als huisartsen zouden werken volgens vaste afspraken (richtlijnen) kan dat ervoor zorgen dat psychische klachten beter herkend, behandeld en gevolgd worden.

De huisarts moet deze richtlijnen aanpassen aan mensen met een verstandelijke beperking.

# Hoofdstuk 3

## Hoeveel van de mensen met een lichte verstandelijke beperking komt bij de huisarts met psychische problemen?
## Wat voor soort psychische problemen zijn dit en welke zorg krijgen ze dan?

### Wat wilden we weten?

We wilden weten:

- hoeveel van de mensen met een lichte verstandelijke beperking bij de huisarts kwamen met psychische problemen;
- met welke psychische problemen ze bij de huisarts kwamen;
- welke zorg ze kregen bij de huisarts.

We wilden ook weten of dit anders is dan bij mensen zonder verstandelijke beperking.

### Wat hebben we gedaan?

In Nederland wordt van veel mensen bijgehouden welke zorg ze hebben gekregen van de huisarts en waarom.
Deze gegevens worden op een vaste plek in Nederland verzameld.
We hebben in deze gegevens gekeken.

### Wat zijn we te weten gekomen?

Meer mensen met een lichte verstandelijke beperking komen bij de huisarts komen met psychische problemen dan mensen zonder verstandelijke beperking.
Verder valt op dat mensen met een lichte verstandelijke beperking en psychische problemen:

- jonger zijn;
- met ander soort psychische klachten komen;
- meer afspraken bij de huisarts hebben;
- vaker medicijnen bedoeld voor psychose voorgeschreven krijgen.

Van elke tien mensen met een lichte verstandelijke beperking,
wordt er maar bij twee mensen opgeschreven dat ze een lichte verstandelijke beperking hebben.
Van de andere acht wordt dat niet genoteerd.

# Hoofdstuk 4

## Met wat voor psychische problemen komen mensen met een lichte verstandelijke beperking in de Geestelijke Gezondheidzorg (GGZ) en welke zorg krijgen ze dan?

### Wat wilden we weten?

We wilden weten:

- met welke psychische problemen mensen met een lichte verstandelijke beperking bij de GGZ kwamen;
- welke hulp ze hebben gekregen bij de GGZ;
- of het bij de GGZ opgeschreven was dat iemand een lichte verstandelijke beperking heeft.

We wilden ook weten of dit anders is dan bij mensen zonder verstandelijke beperking.

### Wat hebben we gedaan?

In Nederland wordt van alle mensen bijgehouden welke zorg ze hebben gekregen in de GGZ en waarom.
Deze gegevens worden op een vaste plek in Nederland verzameld.
We hebben in deze gegevens gekeken.

### Wat zijn we te weten gekomen?

Als je mensen met een lichte verstandelijke beperking vergelijkt met mensen zonder verstandelijke beperking, valt op dat dat mensen met een lichte verstandelijke beperking:

- jonger zijn;
- ander soort psychische problemen hebben;
- minder vaak behandeling krijgen;
- er vaker overleg nodig is met mensen buiten de GGZ;
- vaker met een crisis te maken krijgen;
- vaker opgenomen worden in de GGZ.

Van elke tien mensen met een lichte verstandelijke beperking,
wordt er maar bij vier mensen opgeschreven dat ze een lichte verstandelijke beperking hebben.
Van de andere zes wordt dat niet genoteerd.

# Hoofdstuk 5

## Hoe denken mensen met een lichte verstandelijke beperking over de psychische zorg die ze hebben gekregen van de huisarts?

### Wat wilden we weten?

We wilden weten hoe mensen met een lichte verstandelijke beperking denken over de psychische zorg die ze hebben gekregen van de huisarts.
Wat vonden ze fijn?
Wat vonden ze minder fijn?
Wat zou beter kunnen?

### Wat hebben we gedaan?

We hebben elf interviews gehouden met mensen met een lichte verstandelijke beperking.
Deze mensen hadden allemaal ervaringen met psychische zorg bij de huisarts.
Deze interviews hebben we uitgewerkt in teksten.
Die teksten zijn we gaan lezen.

### Wat zijn we te weten gekomen?

Vier onderwerpen kwamen steeds weer terug in de teksten.
Per onderwerp hebben we opgeschreven wat ons is opgevallen.

### 1. Deelnemers voelden zich kwetsbaar bij de huisarts

Door de psychische problemen was het soms extra lastig om naar de huisarts te gaan.
Dit komt doordat deelnemers:

- niet altijd wisten dat hun klachten psychisch waren;
- niet altijd wisten dat je ook naar de huisarts kon gaan met psychische klachten;
- bezorgd waren dat de huisarts hen niet serieus zou nemen;
- de huisarts niet altijd begrepen;
- niet altijd voldoende steun van begeleiders en familie kregen als ze naar de huisarts gingen;

- vroeger slechte ervaringen hebben gehad met een huisarts of andere zorgverlener.

## 2. Wat deelnemers nodig hebben van de huisarts

Deelnemers vonden het belangrijk dat de huisarts:

- zorgt dat ze makkelijk terecht kunnen met psychische problemen;
- zorgt dat ze zich op hun gemak voelen;
- vraagt hoe het met hen gaat;
- hen goed kent;
- makkelijke taal gebruikt;
- meedenkt over hoe ze de adviezen thuis kunnen uitvoeren;
- weet welke zorgverleners bij hen betrokken zijn en wat ze doen;
- hun begeleider of familie erbij haalt als ze daar toestemming voor geven.

## 3. Wat deelnemers nodig hebben van begeleiders en familie

Deelnemers vonden het belangrijk dat begeleiders en familie:

- een psychische probleem bij hen kunnen herkennen;
- hen aanmoedigen om naar de huisarts te gaan als ze psychische problemen hebben;
- hen helpen om de huisarts te begrijpen;
- meedenken over hoe ze adviezen van de huisarts thuis kunnen uitvoeren;
- er voor hen zijn als ze niet lekker in hun vel zitten.

## 4. Zelf mogen beslissen

Deelnemers vonden het belangrijk dat de huisarts goed luistert naar hun mening.
Ook als er begeleiders of familie betrokken zijn, blijft dit belangrijk.

# Hoofdstuk 6

## Hoe denken huisartsen en praktijkondersteuners (POH’s) over de psychische zorg die ze geven aan mensen met een lichte verstandelijke beperking?

### Wat wilden we weten?

We wilden weten hoe huisartsen en praktijkondersteuners denken over de psychische zorg die ze geven aan mensen met een lichte verstandelijke beperking.
Wat gaat er goed?
Wat gaat er minder goed?
Wat zou beter kunnen?

### Wat hebben we gedaan?

We hebben vier groepsgesprekken gehouden met negentien huisartsen en negen praktijkondersteuners.
Deze gesprekking gingen over de psychische zorg die ze geven aan mensen met een lichte verstandelijke beperking.
Deze gesprekken hebben we uitgewerkt in teksten.
Die teksten zijn we gaan lezen.

### Wat zijn we te weten gekomen?

Vier onderwerpen kwamen steeds weer terug in de teksten.
Per onderwerp hebben we opgeschreven wat ons is opgevallen.

1. **Huisartsen en praktijkondersteuners vinden het soms lastig om de goede zorg te geven.**
   Dit komt doordat:
   - de patiënt niet altijd met een duidelijke vraag om hulp komt;
   - er vaak veel problemen zijn op hetzelfde moment;
   - de richtlijnen van huisartsen niet altijd te gebruiken zijn bij patiënten met een lichte verstandelijke beperking;
   - de patiënt de adviezen van de huisarts, thuis niet altijd goed kan uitvoeren;
   - de lichte verstandelijke beperking de huisarts niet altijd opvalt.

Wat kan **helpen,** is als huisartsen en praktijkondersteuners:

- meer kennis en ervaring hebben over mensen met een lichte verstandelijke beperking en psychische problemen;
- erop letten dat deze patiënten extra hulp krijgen, binnen en buiten de huisartsenpraktijk;
- weten hoe ze een lichte verstandelijke beperking kunnen herkennen;
- in de gegevens van de patiënt opschrijven dat deze een lichte verstandelijke beperking heeft.

### 2. Een goed dokter-patiëntcontact is belangrijk, maar soms ook best moeilijk.

Een goed dokter-patiëntcontact:

- is extra belangrijk bij patiënten met een lichte verstandelijke beperking en psychische problemen;
- kan lastig zijn als patiënten vroeger een slechte ervaring hebben gehad met een huisarts of zorgverlener;
- kan lastig zijn omdat de huisarts het moeilijk vindt om zich goed in te leven in de patiënt.

Wat kan **helpen,** is als huisartsen en praktijkondersteuners:

- steeds dezelfde persoon zijn;
- extra tijd en aandacht geven aan de patiënt;
- duidelijk en rustig zijn;
- makkelijke taal gebruiken.

### 3. Familie en begeleiders van de patiënt zijn belangrijk, maar maken het soms ook lastig.

Familie en begeleiders kunnen zowel de patiënt als de huisarts helpen.
Maar soms weten familie en begeleiders niet hoe ze kunnen helpen.
Of een patiënt heeft geen familie en begeleiders.
Soms maken familie en begeleiders de problemen van een patiënt extra moeilijk.

Wat kan **helpen,** is als:

- huisartsen en praktijkondersteuners de familie en begeleiders erbij halen;
- huisartsen en praktijkondersteuners de familie en begeleiders voldoende informatie en steun geven;
- familie en begeleiders langere tijd bij een patiënt betrokken blijven;
- familie en begeleiders meedenken over het uitvoeren van de adviezen bij de patiënt thuis;
- familie en begeleiders de patiënt steunen als deze niet lekker in zijn vel zit.

### 4. Samenwerken met andere zorgverleners kan uitdagend zijn.

Het is voor de huisarts en praktijkondersteuner vaak moeilijk om de juiste zorg te vinden voor mensen met een lichte verstandelijke beperking en psychische problemen.

- Vaak krijgen patiënten zorg van meerdere zorgverleners.
- Het is dan niet altijd duidelijk wie wat doet.
- Het is niet altijd duidelijk hoe de zorg betaald wordt.
- Er zijn vaak lange wachttijden voor extra zorg.
- Niet alle zorgverleners hebben kennis over patiënten met een lichte verstandelijke beperking.

Wat kan **helpen,** is als:

- huisartsen en praktijkondersteuners weten waar ze juiste zorg en ondersteuning kunnen regelen of hier hulp bij krijgen;
- zorgverleners voldoende plek hebben om patiënten snel te kunnen helpen;
- huisartsen en praktijkondersteuners makkelijk in contact kunnen komen met andere zorgverleners;
- alle zorgverleners en de patiënt samen afspraken maken over wie wat doet;
- alle zorgverleners informatie over de patiënt met elkaar delen;
- steeds dezelfde zorgverleners betrokken zijn;
- alle zorgverleners kennis hebben over patiënten met een lichte verstandelijke beperking.

# Hoofdstuk 7

## Wat zijn we in het onderzoek te weten gekomen en wat kunnen we ermee?

### Wat wilden we aan het begin van het onderzoek weten?

Met dit onderzoek wilden we meer te weten komen over de psychische zorg bij de huisarts aan mensen met een lichte verstandelijke beperking.
Ook wilden we weten hoe we de psychische zorg bij de huisarts kunnen verbeteren.

Dit wilden we weten omdat de huisarts vaak de eerste dokter is waar iemand met psychische problemen naartoe gaat.
Het is belangrijk dat mensen daar meteen de juiste zorg en steun krijgen.
Daarom willen we de huisartsen helpen om de juiste zorg en steun te geven aan deze mensen.

### Wat zijn we te weten gekomen?

We zijn meer te weten gekomen over mensen met een lichte verstandelijke beperking die bij de huisartsen komen met psychische problemen.
We weten nu dat:

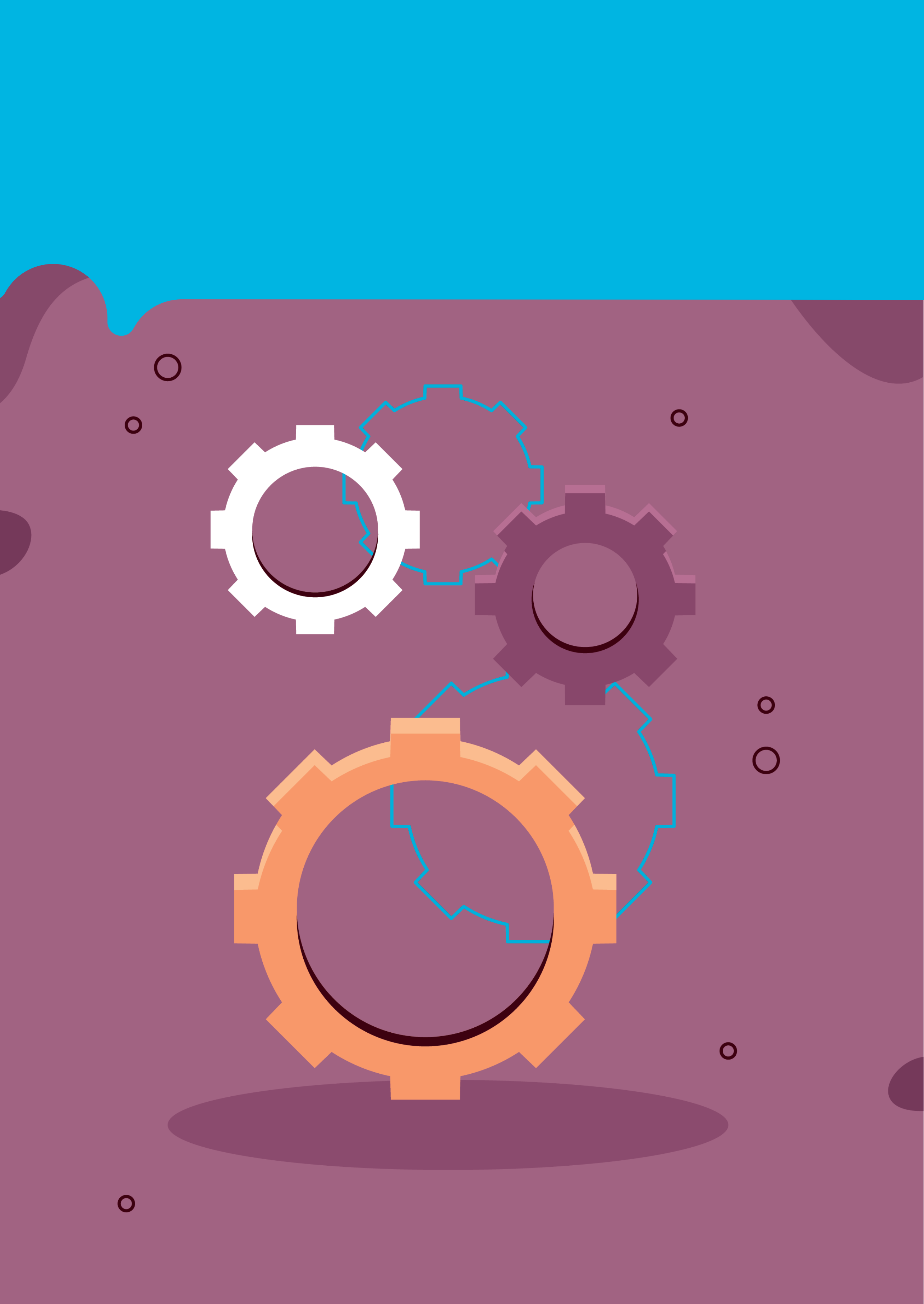
- ze vaak jong zijn;
- vaak veel problemen op hetzelfde moment hebben;
- steun nodig hebben van familie, vrienden, of begeleiders;
- niet altijd voldoende behandeling krijgen in de GGZ;
- de lichte verstandelijke beperking niet altijd herkend wordt door zorgverleners;
- bij psychische problemen de huisarts extra belangrijk is;
- ze vaak een afspraak bij de huisarts maken;
- zich kwetsbaar voelen bij de huisarts;
- extra steun nodig hebben van de huisarts.

### Hoe zou de zorg beter kunnen worden?

Uit het onderzoek komen vijf manieren naar voren die de zorg bij de huisarts zouden kunnen verbeteren.

1. **De huisarts herkent een lichte verstandelijke beperking zo vroeg mogelijk.**
   Het is belangrijk dat huisartsen en praktijkondersteuners leren:
   - hoe ze een lichte verstandelijke beperking kunnen herkennen;
   - hoe ze dit bespreken met de patiënt;
   - hoe ze hun taal hierop aanpassen;
   - hoe ze zorgen dat de juiste hulp gegeven wordt.
2. **Er is altijd dezelfde huisarts betrokken bij een patiënt.**
   Het is goed als dezelfde huisarts voor een lange tijd voor een patiënt kan zorgen.
   Maar soms is dit moeilijk om te regelen.
   Soms is dit makkelijker te regelen voor een praktijkondersteuner.
3. **Familie, vrienden en begeleiders helpen de patiënt.**
   Familie, vrienden en begeleiders kunnen de patiënt en de huisarts helpen.
   Maar soms weten ze niet goed hoe ze dit moeten doen.
   Dan is het belangrijk dat ze extra hulp krijgen.
   Het is ook belangrijk dat ze goed met de huisarts samenwerken.
4. **De huisarts moet veel weten over mensen met een lichte verstandelijke beperking en psychische problemen.**
   Er is te weinig wetenschappelijke kennis hierover.
   Dokters moeten daarom extra leren van hun eigen ervaringen.
   Het is goed als dokters al vroeg in hun opleiding leren over patiënten met een lichte verstandelijke beperking.
   Als ze geen ervaring hebben, kunnen ze leren van andere dokters die meer ervaring hebben met deze patiënten.
5. **De verschillende zorgprofessionals werken goed met elkaar samen.**
   Patiënten hebben vaak hulp nodig van verschillende soorten dokters en andere zorgverleners.
   Het is voor de huisarts moeilijk om de juiste mensen te vinden.
   Soms werken de verschillen zorgverleners niet goed samen.
   Gelukkig zijn er voorbeelden van goed samenwerken waar we van kunnen leren.

De huisarts kan de psychische zorg voor deze patiënten niet alleen verbeteren.
De huisarts zal geholpen moeten worden door andere zorgverleners,
mensen die beslissingen maken over de regels en het geld,
en door mensen die onderzoek doen.



# Chapter 9

# Research data management

## Ethics and privacy

Chapters 3 to 6 of this thesis are based on the results of medical-scientific research with human participants. All four studies were reviewed by the Medical Research Ethics Committee East-Netherland, which ruled that these studies were not subject to the Medical Research Involving Human Subjects Act (Chapters 3 and 4, file number 2017-3921; Chapters 5 and 6, file number 2022-13687). In all studies, both the General Data Protection Regulations and the Dutch code for Scientific Integrity were followed. In addition, the studies described in Chapters 3 and 4 were conducted according to the Netherlands Institute for Health Services Research (NIVEL) and Statistics Netherlands (SN) governance code.

In order to guarantee patients' privacy, SN linked the NIVEL and SN datasets for the studies in Chapters 3 and 4. Participants in the studies in Chapters 5 and 6 were required to provide written informed consent, and the signed papers, stored in restricted lockers, will be archived after completion of the studies. The participants' privacy is guaranteed by the use of encrypted individual subject codes. These codes are stored separately from the pseudonymized study data on the department server, and access is restricted to three members of the research team.

## Data collection and storage

The data for Chapters 3 and 4 were collected and analysed and are now stored on the SN server and accessible only to those team members who have obtained SN permission. Final data were released outside the SN server only after SN had determined that their institution privacy requirements were met. These final data together with the pseudonymized transcripts of Chapters 5 and 6 are stored on the Radboudumc department server. Access to the project folder is restricted to team members who are registered in the department quality system.

## Availability of data

All studies are open-access published. The data will be archived for 15 years after the study terminates. Aggregated data from the databases used in Chapters 3 and 4 are publicly available on a dedicated SN website (http://statline.cbs.nl) and NIVEL website (https://www.nivel.nl/en/nivelzorgregistraties-eerste-lijn/nivel-primary-care-database). The non-public microdata used to link the databases are, under certain conditions, accessible for statistical and scientific research (fees apply). Procedures can be found at (www.cbs.nl) and (www.nivel.nl). The final data in Chapters 3 and 4 are available from the corresponding author upon reasonable request. Reuse of the pseudonymized transcripts of Chapters 5 and 6 for future research is possible only after renewed permission from the participants.

# Chapter 10

## Dankwoord
## List of publications
## Curriculum Vitae
## Portfolio

# Dankwoord

Het laatste hoofdstuk. Je zou zeggen dat dit het makkelijkste hoofdstuk is om te schrijven. Maar toch duizelt het me. Wat zijn de afgelopen vijf jaar snel gegaan, zo veel mensen hebben me op allerlei manieren geïnspireerd, gemotiveerd en gesteund. Daarvoor ben ik ontzettend dankbaar. Een aantal mensen wil ik graag persoonlijk bedanken:

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Bedankt **'s Heeren Loo** dat jullie me de ruimte hebben gegeven om dit onderzoek naast mijn werk als arts VG uit te voeren. In het bijzonder wil ik bedanken **Bas Bijl, Edith Rijnsburger** en mijn **collega's van de medische dienst in Apeldoorn**. Ik mis de gezelligheid op de medische dienst nog elke week. Bedankt voor jullie steun op vele vlakken van afgelopen jaren.

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# List of publications

## Peer reviewed

Pouls KPM, Mastebroek M, Ligthart SJ, Assendelft WJJ, Leusink GL, KoksLeensen MCJ. Primary mental healthcare for adults with mild intellectual disabilities: care professionals' perspectives. BJGP Open. Accepted April 2024.*(This thesis)*

Pouls KPM, Mastebroek M, Ligthart SJ, Assendelft WJJ, Leusink GL, Koks-Leensen MCJ. Primary mental healthcare for adults with mild intellectual disabilities: patients' perspectives. EJGP. 2024;30(1) *(This thesis)*

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Cuypers M, Leijssen M, Bakker-van Gijssel EJ, Pouls KPM, Mastebroek M, Naaldenberg J, Leusink GL. Patterns in the prevalence of diabetes and incidence of diabetic complications in people with and without an intellectual disability in Dutch primary care: Insights from a population-based data-linkage study. Prim Care Diabetes, 2021 Apr;15(2):372-377

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# Curriculum Vitae

Katrien Pouls was born on 1 August 1978 in ‘s-Hertogenbosch. When she was one year old, she moved with her parents and older brother, Gijs, to Sint-Michielsgestel, where her parents still live. After completing her secondary education in 1996 at Skinle College in Schijndel, now known as Elde College, she started her medical training in Maastricht. During her studies, she held various extracurricular positions, serving as a student assistant in research projects for the departments of psychology and vascular surgery at Maastricht University Medical Center. Additionally, she was a member of both the regional and national boards of The Netherlands Medical Students’ International (NeMSIC), now known as the International Federation of Medical Students’ Associations (IFMSA), where she met her husband Herjan. As a medical professional, Katrien began her career at Elkerliek Hospital in Helmond in the paediatric department and later in internal medicine as a postgraduate house officer. Her interest in internal medicine led her to start the internal medicine residency at Maxima Medisch Centrum in Veldhoven in 2004. In 2007, she switched to the position of intellectual disability (ID) physician resident at Lunet Zorg in Eindhoven. The holistic approach to patients, having more time for each patient, and the multidisciplinary approach better aligned with Katrien’s vision of being a physician. After completing her training, she began working as an ID physician at Pluryn, Winckelsteegh location, where she also served as a Compulsory Admission (BOPZ) doctor for several years. In 2012, she undertook the postgraduate training in Ethics in the Healthcare Sector, following which she became a member of the Ethics Advisory Group of the Dutch Association of ID Physicians (NVAVG) for seven years. In 2015, she decided to part ways with Pluryn and started working as an ID physician at ‘s Heeren Loo in Apeldoorn. Here, she developed a passion for people with mild ID, laying the foundation for her doctoral research, which she commenced in 2019. Currently, Katrien works as an ID physician at Ment GGZ in Velp and as a senior project assistant at the National Knowledge Centre for Mild ID in Utrecht. With this, she has found the perfect balance between practice and (scientific) knowledge. Herjan and Katrien got married in 2022 and have three children: Tom (2009), Max (2012), and Lotte (2013). The family lives in Ooij.

Katrien Pouls werd geboren op 1 augustus 1978 in ‘s Hertogenbosch. Toen ze één jaar oud was, verhuisde ze samen met haar ouders en oudere broer Gijs naar Sint-Michielsgestel waar haar ouders nog steeds wonen. Nadat ze in 1996 haar VWO afrondde op het Skinle College in Schijndel, tegenwoordig het Elde College, ging ze geneeskunde studeren in Maastricht. Al tijdens haar studie had ze verschillende nevenfuncties. Zo was ze een aantal jaren als student-assistent betrokken bij onderzoeken van de afdeling psychologie en vaatchirurgie van Maastricht UMC. Daarnaast was ze lid van zowel het regionale als landelijk bestuur van ‘The Netherlands Medical Students’ International’ (NeMSIC), tegenwoordig International Federation of Medical Students’ Associations (IFMSA), waar ze ook haar man Herjan ontmoette. Als arts begon Katrien haar carrière in het Elkerliek ziekenhuis in Helmond bij de afdeling kindergeneeskunde en later bij de afdeling interne geneeskunde als arts niet in opleiding. De interne geneeskunde sprak haar dusdanig aan dat ze in 2004 aan de opleiding interne geneeskunde in het Maxima Medisch Centrum in Veldhoven begon. In 2007 stapte ze over naar de opleiding voor arts voor verstandelijke gehandicapten (arts VG). De holistische kijk op patiënten, meer tijd hebben voor de patiënt en de multidisciplinaire benadering sloten beter aan bij de manier waarop Katrien arts wilde zijn. Haar opleiding volgde ze bij Lunet Zorg in Eindhoven. Na haar opleiding ging ze in 2010 werken als arts VG bij Pluryn, locatie Winckelsteegh, waar ze ook enkele jaren BOPZ arts was. In 2012 volgde ze de postacademische opleiding Ethiek in de Zorgsector, waarna ze aansluitend zeven jaar lid was van de Adviesgroep Ethiek van de Nederlandse Vereniging Artsen Verstandelijk Gehandicapten (NVAVG). In 2015 besloot ze afscheid te nemen van Pluryn en begon ze als arts VG bij ’s Heeren Loo locatie Apeldoorn. Hier ontwikkelde ze haar passie voor mensen met een lichte verstandelijke beperking en ontstond haar idee voor haar promotieonderzoek waar ze in 2019 mee is gestart. Momenteel werkt Katrien als arts VG bij Ment GGZ in Velp en als senior projectmedewerker bij het Landelijk Kenniscentrum LVB in Utrecht. Hiermee heeft ze de perfecte balans gevonden tussen praktijk en (wetenschappelijke) kennis. Herjan en Katrien trouwden in 2022 en hebben samen drie kinderen: Tom (2009), Max (2012) en Lotte (2013). Het gezin woont in Ooij.

# Portfolio

Department: **Primary and community care**
PhD period: **01-03-2019 – 01-03-2024 (0.4 fte)**
PhD Supervisor(s): **Prof. dr. G.L. Leusink & Prof. dr. W.J.J. Assendelft**
PhD Co-supervisor(s): **Dr M.C.J. Koks-Leensen & Dr. M. Mastebroek**

| **Training activities** | **Hours** |
|---|---|
| **Courses** | |
| - BROK basic course (2019) | 42.00 |
| - Introduction course qualitative research in healthcare (2019) | 22.40 |
| - RIHS PhD introduction course (2019) | 21.00 |
| - RIHS course for PhD candidates (2019) | 15.00 |
| - Statistics for PhD candidates with SPSS, refresher course (2021) | 56.00 |
| - Scientific Writing for PhD candidates (2021) | 84.00 |
| - The Art of Presenting Science (2021) | 42.00 |
| - Radboudumc scientific integrity course (2022) | 20.00 |
| - eBROK re-registration course (2023) | 26.00 |
| - Social media workshop (2023) | 2.00 |
| - Data management plan workshop (2023) | 2.00 |
| - Design and Illustration (2023) | 26.00 |
| - How to nail your PhD defence (2024) | 2.00 |

## Conferences

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|---|---|
| - Treatment of patients with a low IQ in mental health services, GGZ congresses; poster (2019) | 14.00 |
| - World congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID); oral (2019) | 36.00 |
| - European congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID); oral (2021) | 30.00 |
| - European congress Association for Mental Health in Intellectual Disability (EAMHID); oral (2021) | 30.00 |
| - European Public Health Conference (EPH); oral (2021) | 12.00 |
| - Europe conference World Organisation of Family Doctors (WONCA); oral (2023) | 36.00 |
| - Public health fair, HAN University (2023) | 4.00 |
| - Work conference integrative mental healthcare, UMCU (2023) | 6.00 |
| - Every person counts: inclusive care, education, and research, Radboudumc (2023) | 4.00 |
| - Research day Dutch GP Organisation (NHG); oral (2023) | 14.00 |
| - Regional domain transcending mental health care, Proscoop; oral (2024) | 4.00 |

## Other

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|---|---|
| - Work retreat, department Healthcare for people with intellectual disabilities, Radboudumc (2022) | 6.00 |
| - Work conference department of Public health, UMCU; oral (2023) | 4.00 |
| - Knowledge Circle Radboud Academic Collaborative Addiction Centre, Radboudumc (2023) | 2.00 |
| - Work retreat, department Healthcare for people with intellectual disabilities, Radboudumc (2023) | 18.00 |

## Lecturing

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|---|---|
| - Presentation Dutch Association Intellectual Disabilities Physicians (NVAVG), Arnhem region; oral (2020) | 14.00 |
| - Presentation Dutch Association Intellectual Disabilities Physicians (NVAVG), Arnhem region; oral (2021) | 14.00 |
| - Intellectual disabilities physicians 's Heeren Loo, location Apeldoorn; oral (2021) | 6.00 |
| - Intellectual disabilities physicians year group 2007; oral (2021) | 6.00 |
| - Meet the PhD, Radboudumc; oral (2023) | 2.00 |
| - General practitioners organisation Eemland; oral (2023) | 12.00 |
| - Intellectual disabilities physicians year group 2007; oral (2023) | 6.00 |
| - Lectures to master's students in medicine, Radboudumc; oral (2024) | 20.00 |
| - Intellectual disabilities physicians 's Heeren Loo; oral (2024) | 4.00 |

## Supervision of internships / other

| | |
|---|---|
| - Supervision master research student, Radboudumc (2020) | 28.00 |
| - Supervision bachelor research student, Radboudumc (2020) | 28.00 |
| | **720.40** |

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's Heeren Loo

Radboudumc
university medical center